

## DOCUMENT RESUME

ED 323 699

EC 232 127

TITLE Reimbursement for Medical Genetics Services: A  
Selected Bibliography.

INSTITUTION Connecticut Univ., Farmington. Div. of Human  
Genetics.

SPONS AGENCY National Center for Education in Maternal and Child  
Health, Washington, DC.

PUB DATE May 87

CONTRACT MCJ-09100-030

NOTE 51p.

PUB TYPE Reference Materials - Bibliographies (131)

EDRS PRICE MF01 Plus Postage. PC Not Available from EDRS.

DESCRIPTORS \*Congenital Impairments; \*Delivery Systems;  
\*Genetics; Health Care Costs; \*Health Insurance;  
Health Services; Heredity; \*Medical Services

## ABSTRACT

This bibliography cites genetics literature identified during a project to investigate the issue of accessibility to genetics services through the reimbursement process. Citations represent both traditional published literature and such "fugitive literature" as unpublished manuscripts, government documents, service provider protocols, and health policy documents. The entries are organized into 13 categories: accessibility, chronic care (long term care), consumer issues, cost containment and reimbursement, general definitions, ethics, genetics funding, health insurance, health maintenance organizations, international issues, Medicaid/Medicare, new technologies, and quality control. (JDD)

\*\*\*\*\*  
\* Reproductions supplied by EDRS are the best that can be made \*  
\* from the original document. \*  
\*\*\*\*\*

# REIMBURSEMENT FOR MEDICAL GENETICS SERVICES:

## A Selected Bibliography



**NCEMCH**

National Center for Education in  
Maternal and Child Health  
38th and R Streets, NW  
Washington, DC 20057  
(202) 625-8400



Division of Human Genetics  
Department of Pediatrics  
University of Connecticut Medical School  
Farmington, CT 06032  
(203) 679-2676

# TABLE OF CONTENTS

	Page
Acknowledgements .....	..ii
Preface .....	..iii
Definition of Categories .....	..iv
Categories	
1. Accessibility .....	1
2. Chronic Care (Long Term Care) .....	6
3. Consumer Issues .....	9
4. Cost Containment/Reimbursement .....	11
5. General Definitions .....	18
6. Ethics .....	22
7. Genetics Funding .....	26
8. Health Insurance .....	28
9. HMOs/IPAs .....	31
10. International Issues .....	33
11. Medicaid/Medicare .....	35
12. New Technologies .....	38
13. Quality Control .....	42

## ACKNOWLEDGEMENTS

The authors would like to express their sincere appreciation to the members of our project staff who worked long to produce this bibliography: Fran Erba, secretary; Debra Young, research assistant; Susan Streib, computer analyst; Leigh Dalkowski, library research; Linda Procko, typist; Eunice Killen, administrator; and Mary Ellen Beyer, production specialist.

We are indebted to the Genetic Disease Services Branch, MCH (DHHS) for their support, especially Mr. Rudolf Hormuth, Regional Coordinator, and to the New England Regional Genetics Group (NERGG) under the guidance of Alan Crocker, M.D., Richard Erbe, M.D. and Stacy Kacyanis, M.S., co-directors.

The National Center for Education in MCH (NCEMCH) staff has been extremely helpful and we wish to thank Mark Odum, Edward Rorie, Anna Hamilton, Kate Oliver and Rochelle Mayer for their support and advice.

Robert M. Greenstein, M.D.

Gale B. Gardiner, M.S.

## PREFACE

This bibliography evolved as a product of many hours of information acquisition and library research during the first two project years of a three year Maternal and Child Health SPRANS grant, "Assessment of Reimbursement for Genetic Services" (DHHS, BHCDA, MCH Genetics Disease Services Branch, Grant No. MCJ-09100-030). The project has been carried out by staff of the Division of Human Genetics, Department of Pediatrics, University of Connecticut Medical School.

The central mission of this project is to develop a financial demographic data base from 19 genetic centers throughout New England derived from a full year's billing-reimbursement experience from each center and a description of their organizational structure and personnel. In addition to an assessment of direct genetics service billings (professional fees, procedures and laboratory tests), an attempt was made to examine contiguous or collaborative services, such as contributing departments of pathology, radiology and obstetrics-gynecology. The objective of this data collection was to investigate the issue of accessibility to genetics services through the reimbursement process. This permitted us the opportunity to construct a profile of third party payors for each institution (payor mix) and relate this profile to the demographic characteristics of each institution's geographic region.

The project also developed investigations of reimbursement by Medicaid for all 50 states; a survey of HMO's and managed care providers in New England; a description of the satellite programs for each of the genetics centers; an analysis of MSAFP utilization throughout New England from 1983-1985; an international survey of reimbursement practices in 20 countries, and a survey of New England Regional Genetics Group members to develop a working definition of a "comprehensive genetics center".

The traditional genetics literature surveyed during the project revealed relatively few articles that specifically addressed the issues of reimbursement and accessibility. However, the search into related fields of health economics, health care planning, Medicaid/Medicare, health insurance and health care and hospital administration proved fruitful, albeit not focused on genetics services. In addition, our research led us into the "fugitive literature" of unpublished manuscripts, governmental agency documents, service provider protocols and health policy documents.

In order to organize this heterogeneous array of articles, the authors developed a cross-indexed set of 13 literature categories for ease of retrieval. This will be described in the next section.

It should be understood that this is a partial or selected bibliography which reflects the activities of our projects. Inclusion does not imply endorsement of the information therein by NCEMCH, the Genetics Disease Services Branch of MCH or the University of Connecticut Medical School. Readers are invited to expand the contents of the bibliography in any manner they choose. We would appreciate your sharing those references and documents with us in order to continue to expand this bibliography.

Robert M. Greenstein, M.D.  
Project Director

Gale B. Gardiner, M.S.  
Project Coordinator

Division of Human Genetics  
University of Connecticut Medical School  
Farmington, CT 06032

## DEFINITION OF CATEGORIES

The authors have organized the bibliographic material into 13 categories which may be cross-indexed by their category codes. Each reference is coded by both a primary and secondary category. The primary code signifies the principal emphasis of the reference. If there was an additional strong emphasis in the reference, a secondary code was also assigned. Therefore, a large proportion of references are found to be cross-indexed against two category codes.

The following is a listing of the categories, each with a brief description of its content.

- AC **Accessibility**—Limiting factors that may affect the availability of health services to any population
- CC **Chronic Care (Long Term Care)**—Studies addressing the unique problems of conditions requiring long term or chronic care
- CN **Consumer Issues**—Articles focusing on the accessibility of medical genetics services from the consumer perspective
- CR **Cost Containment/Reimbursement**—Studies addressing policy issues of cost benefit, cost control, cost sharing, diagnostic related groups (DRGs) and reimbursement
- GD **General Definitions**—Descriptive articles that provide background information on personnel, technologies, and phenomena pertaining to the study of reimbursement for genetic disease
- ET **Ethics**—Articles concerning the promise and perils of new and not so new technologies—how ethics may affect public policy considerations
- GF **Genetics Funding**—Past, present and future methods of funding genetics services including government (i.e., local, state, federal and grants)
- HI **Health Insurance (Commercial)**—Issues involving commercial health insurance reimbursement methods—past, present and future
- HM **Health Maintenance Organizations (HMOs) and Individual Physician Associations (IPAs)**—Historical, current and future commentaries on the evolution of HMOs and IPAs—specifically as it may apply to the offering of and reimbursement for genetics services
- IN **International Issues**—Articles that address international concerns regarding the accessibility and economics of medical genetics
- MM **Medicaid/Medicare**—Medicaid and Medicare policies on, and experiences with, reimbursement for different types of medical services
- NT **New Technologies**—Services not currently used on a routine basis, or not routinely available to the public for more than 10 years—how new technologies become incorporated into general practice
- QC **Quality Control**—Issues affecting the acceptable level of service quality offered to the public including accreditation, licensing and legal ramifications which may, in turn, affect reimbursement

## CATEGORY 1—ACCESSIBILITY

### A. Primary References

- Abrams S, Wassel N. Health-Care Crisis Won't Cure Itself. *The Hartford Courant*. Dec. 3, 1986.
- Abuelo DN, Rosenstein J, Sheff M. Tay-Sachs Disease: Knowledge and Attitudes of the Rabbinical Community. *RI Med J*. 1985; 68:225-6.
- Andrews LB. State Laws and Regulations Governing Newborn Screening. American Bar Foundation, Chicago. 1985; 167.
- Annas GJ, Elias S. Maternal Serum AFP: Educating Physicians and the Public. *AJPH*. 1985; 75:1374-5.
- Banta D, Behney CJ. Medical Technology: Policies and Problems. *HCM Review*. Fall 1980; 45-52.
- Beeson D, Golbus MS. Decision Making: Whether or Not to Have Prenatal Diagnosis and Abortion for X-Linked Conditions. *Am J Med Gen*. 1985; 20:107-14.
- Benn PA, Hsu LYF, Carlson A, et al. The Centralized Prenatal Genetics Screening Program of New York City III: The First 7,000 Cases. *Am J Med Genet*. 1985; 20:369-84.
- Berger LR. Abortions in America: The Effects of Restrictive Funding. *N Engl J Med*. 1978; 298:1474-7.
- Berki SE, Wyszewianski L, Magilavy LJ, et al. Families With High Out-Of-Pocket Health Services Expenditures Relative to Their Income. U.S. Department of Health and Human Services. Jan. 30, 1985.
- Blendon RJ. Over 24 Million in U.S. Lack Access to Health Care. *Pediatric News*. April 1984; p28.
- Briard ML, Kaplan J, Merrer ML, et al. Impact Du Conseil Genetique Sur La Fecondite des Couples. *J Genet Hum*. 1984; 32:257-63.
- Chan CK. Eugenics on the Rise: A Report from Singapore. *Int J Health Services*. 1985; 15:707-12.
- Childs B, Huether CA, Murphy EA. Human Genetics Teaching in U.S. Medical Schools. *Am J Hum Genet*. 1981; 33:1-10.
- Colburn D. How many aren't covered? The equivalent of the nation's 36 largest cities. *Washington Post*. July 21, 1986; 11-3.
- Connell FA, Blide LA, Hanken MA. Clinical Correlates of Small Area Variations in Population-based Admission Rates for Diabetes. *Med Care*. 1984; 22:939-49.
- Council on Maternal and Child Health. Background Paper on Universal maternity Care. *J Publ Health Policy*. 1986; 105-23.
- Curtis R. The Role of State Governments in Assuring Access to Care. *Inquiry*. Fall 1986; 23:277-85.
- Curtiss FR. Recent Developments in Federal Reimbursement for Home Health Care. *Am J Hosp Pharm*. 1986; 43:132-9.
- Daniels N, Miller FH, Miller GAH. Why Saying no to Patients in the United States is so Hard: Cost Containment, Justice, and Provider Autonomy. *N Engl J Med*. May 1986; 314; 21:1380-86.
- Darling H. The Role of the Federal Government in Assuring Access to Health Care. *Inquiry*. Fall 1986; 23:286-95.
- David DH, Hawkins JW. High-Risk Maternal and Neonatal Transport: Psychosocial Implications for Practice. *Dimensions of Critical Care Nursing*. 1985; 4:368-79.
- Dolenc DA, Deugherty CJ. DRGs: The Counterrevolution in Financing Health Care. *Hastings Center Report*. 1985; 19-29.
- Durenberger, Kennedy, Heinz, Riegle. Bill S.2403—A Bill to Amend the Internal Revenue Code of 1954 to Assure Access to Health. 99th Congress, 2nd Session. 1986; 132.
- Fuchs VR. The 'Rationing' of Medical Care. *New Engl J of Med*. Dec. 13, 1984; 311; 24:1572-3.
- Grazier KL, Richardson WC, Martin DP, et al. Factors Affecting Choice of Health Care Plans. *Health Services Research*. 1986; 29:659-82.
- Greer DS. Editorial Draft. *Comparative Health System Newsletter*. Fall, 1986.
- Grossman LK, Holzman NA, Charney E, et al. Neonatal Screening and Genetic Counseling for Sickle Cell Trait. *AJDC*. 1985; 139:124-244.
- Haworth JC, Miller JR. Screening, Counseling and Treatment of Hereditary Metabolic Disease: A Survey of Resources in Canada. *CMAJ*. 1974; 111:1147-55.
- Health Systems Agency of North Central Connecticut. A Managed Health Care Program for Hartford's Low Income Population. Hartford, CT: HSA North Central CT. 1984.
- Heggenhougen HK. Will Primary Health Care Efforts Be Allowed To Succeed? *Soc Sci Med*. 1984; 19:217-24.
- Hibbard BM. Screening for Neural Tube Defects. Results in Practice. *Midwife Health Visitor & Community Nurse*. 1982; 18:460-6.
- Hook EB. Invited Editorial: Genetic Triage and Genetic Counseling. *Am J Med Gen*. 1984; 17:535-538.
- Hormuth RP. State Laws & Regulations on Genetic Disorders. U.S. Dept. of Health & Human Serv. Public Health Serv. Bur. of Comm. Healthy Serv. Gen. Dis. Serv. Branch DHHS Publ #HSA81-5243.
- Iglehart JK. Health Policy Report, The Future Supply of Physicians. *N Engl J Med*. 1986; 314;13:860-4.
- Iglehart JK. Health Policy Report: Federal Support of Health Manpower Education. *N Engl J Med*. Jan. 1986; 314;5:324-28.
- International Medical News Service. Health Care Needs of Children Said to Have Fallen Through Third-Party Coverage Net. *Pediatric News*. 1986; 20;1:3.
- International Medical News Service. States Increasing Care for Medically Indigent. *Pediatric News*. March 1985; p68.

- Ives EJ, Henick P, Morgan K, Hoimes TM. Evaluation of Genetic Counseling following the birth of a Malformed newborn. *Genetics*. Abstract # 833:249A.
- Kuhn ME. Nurses and Patients—Together We Can Heal the Sick Health Care System. *Nurs Health Care*. 1985; 6:363-4.
- Letter to the Editor, Klein WJ. Why Saying No to Patients in the United States is So Hard. *N Engl J Med*. 1986; 315:1296-7.
- Letter to the Editor., Olson-Garewal JK. Cost Containment and the CPC. *N Engl J Med*. 1986; 315:1297.
- Levinsky NG. The Doctor's Master. *The New Engl. J. of Med*. Dec. 13, 1984; 311:24:1573-5.
- Light DW, Liebfried S, Tennstedt F. Social Medicine vs Professional Dominance. The German Experience. *Am J Public Health*. 1985; 75:78-83.
- Lippman-Hand A, Piper M. Prenatal Diagnosis for the Detection of Down Syndrome. Why are so few eligible women tested? *Prenatal Diagnosis*. 1981; 1:249-57.
- Marmor TR, Klein R. Cost vs. Care. America's Health Care Dilemma Wrongly Considered. *Hosp Management Rev*. 1986; 5:11.
- May DP. The Privileged Must Help Cover Hospital Costs of Poor, Elderly. *Hartford Courant*. June 28, 1986; D11.
- McNeil BJ, Pauker SG. Decision Analysis for Public Health: Principles and Illustrations. *Ann Rev Public Health*. 1984; 5:135-61.
- Mechanic D. Health Care for the Poor: Some Policy Alternatives. *J Fam Pract*. 1986; 22:283-9.
- Merz B. Markers for Disease Genes Open New Era in Diagnostic Screening. *JAMA*. 1985; 315:3-9.
- Meyer LS. Untangling Communication Lines to Connect Consumers and Providers. *Nurs Health Care*. 1985; 6:367-8.
- Mitchell JB, Schurman R. Access to Private Obstetrics/Gynecology Services Under Medicaid. *Medical Care*. Nov. 1984; 22,11:1026-37.
- Mohan J, Woods KJ. Restructuring Health Care. The Social Geography of Public and Private Health Care Under the British Conservative Government. *Int J Health Serv*. 1985; 15:197-215.
- Monheit AC, Hagan MM, Berk ML, et al. Health Insurance For The Unemployed. Is Federal Legislation Needed? *Health Affairs*. Spring 1984; 3;1:101-11.
- Mueller RF, Sybert VP, Johnson J, Brown ZA, Chen WJ. Evaluation of a Protocol for Post-Mortem Examination of Stillbirths. *N Engl J Med*. 1983; 309:586-90.
- National Center for Health Services Research and Health Care, Technology Assessment. Grants for Health Services Dissertation Research 1987. U.S. Department of Health and Human Services. July 1986; 1-8.
- Parker AK. Third-Party Payment for Nutrition Care Services. *J Am Dietetic Assoc*. 1984; 84:695-700.
- Passarge E, Eckerland B, Stephan U. Genetic Counselling in Cystic Fibrosis. *Eur J Pediatr*. 1984; 143:54-57.
- Pediatric News. U.S. Budget Cuts Said to Affect Child Health. *Pediatric News*. Oct 1985; 19:22.
- Renner G. Clergy Asks Congregations to Help Poor Get Health Care. *The Hartford Courant*. December 3, 1986; Section C, page 1.
- Sadovnick AD, Baird PA. Maternal Age-Specific Costs of Detecting Down Syndrome and Neural Tube Defects. *Canadian J Pub Health*. 1982; 73:248-50.
- Scott-Samuel A. Screening for Neural Tube Defects. *Lancet*. 1980; 1:550.
- Thurrow LC. Learning to Say 'No'. *New Engl J of Med*. Dec. 13, 1984.; 311:24:1569-72.
- Uzych L. Genetic Testing and Exclusionary Practices in the Workplace. *J Public Health Policy*. 1985; 37-57.
- Van Regemorter N, Dodion J, Druart MA, et al. Congenital malformations in 10,000 consecutive births in a university hospital. *J Pediatrics*. March 1984; 386-390.
- Vekemans M, Lippman A. Letter to the Editor: Response to Invited Editorial by Hook. *Am J Med Gen*. 1984; 17:539.
- Vitello SJ. The Tatro Case: Who Gets What and Why. *Exceptional Children*. 1986; 52:353-6.
- Waitzkin H, Akin BV, de la Maza LM, et al. Deciding Against Corporate Management of a State-Supported Academic Medical Center. *N Engl J Med*. 1986; 315:1299-1304.
- Wennberg JE. Variations in Medical Practice and Hospital Costs. *Conn Med*. 1985; 49:444-53.
- Wertelecki V. Minimal Southeastern Regional Database Proposed Conceptual Items. Personal Communication. 1984; 1-3.
- Williamson RA, Hanson JW, Grant SS. Maternal Serum Alpha-fetoprotein Screening. Report of a Pilot Project in Iowa. *Iowa Medicine*. Feb. 1986; 61-4.



## B. Secondary References—Accessibility

- Akhmeteli MA, Aledort LM, Alexanians S, et al. Methods for the Detection of Hemophilia Carriers: A Memorandum. *Bulletin of the World Health Organization*. 1977; 55:675-702.
- Anlyan WG, Lipscomb J. The National Health Care Trust Plan: A Blueprint for Market and Long-Term Care Reform. *Health Aff*. 1985; 4:5-31.
- Arnett RH. Projections of Health Care Spending to 1990. *Hosp Management Rev*. 1986; 5:10.
- Banta D. On "A Decline in Earning Losses Associated With a Community-Based Cardiovascular Disease Prevention Project" *Med Care*. 1982; 20:661-2.
- Benson Gold R, Kenney AM. Paying for Maternity Care. *Family Planning Perspectives*. May/June 1985; 17:3:103-11.
- Bergner L. Amniocentesis for Sex Identification—Letter to the Editor. *N Engl J Med*. 1980; 302:525.
- Berry HK. The Spectrum of Metabolic Disorders. *Diagnostic Med*. 1984; 39-46.
- Blatt R. What Are Your Clients Reading? *The Genetic Resource*. 1985-86; 2:41-4.
- Blendon RJ, Aiken LH, Freeman HE, et al. Uncompensated Care by Hospitals or Public Insurance for the Poor, Does It Make a Difference. *N Engl J Med*. May 1986; 314:18:1160-4.
- Blim RD, Austin G, Cooper LZ, et al. Medicaid Policy Statement. *Pediatrics*. May 1986; 77:5:762-3.
- Bradshaw J, Lawton D. Utilization of the Family Fund. *Child: Care, Health and Development*. 1982; 8:226:237.
- Bradshaw K. Children's Hospital Association Awarded Grants for Case Mix Payment Project. *NACHRI Reports*. July 1984.
- Brelsford G. The Impacts of Alternative Funding Policies for Ambulatory Care Services on Hospitalization in the Indian Health Service Contract. *Alaska Med*. 1985; 27:2:31-5.
- Brent RL. Ultrasonography in Fetal Diagnosis. *Ped Ann*. 1981; 10:2:49-60.
- Broder H, Trier WC. Effectiveness of Genetic Counseling for Families with Craniofacial Anomalies. *Cleft Palate Journal*. 1985; 22:157-62.
- Butler JA, Singer JD, Palfrey JS, et al. Health Insurance Coverage and Physician Use Among Children With Disabilities: Findings From Probability Samples in Five Metropolitan Areas. *Pediatrics*. Jan. 1987; 79:1:89-98.
- Caring. Medicaid Coverage of the Pediatric Population. *Caring*. May 1985; 52.
- Cereseto S, Waitzkin H. Economic Development, Political-Economic System, and the Physical Quality of Life. *Am J Public Health*. June 1986; 76:6:661-66.
- Clayden C, Mattar N. Ethics and the Severely Malformed Infant: Report on a Multidisciplinary Workshop. *J Med Ethics*. 1984; 2:71-2.
- Comptroller General of the United States. Maternal and Child Health Block Grant: Program Changes Emerging Under State Administration. Report to Congress GAO/HRD-84-35. 1984.
- The Connecticut Hospital Association. The Connecticut Hospital Association 1985-86 Legislative Directory. The Connecticut Hospital Association. 1985.
- Cox CL, Sullivan JA, Roghmann KJ. A Conceptual Explanation of Risk-Reduction Behavior and Intervention Development. *Nurs Res*. 1984; 33:168-73.
- Crawshaw R, Garland MJ, Hines B, et al. Oregon Health Decisions—An Experiment With Informed Community Consent. *JAMA*. 1985; 254:3213-6.
- Curtis R. The Role of State Governments in Assuring Access to Care. *Inquiry*. Fall 1986; 23:277-85.
- Darling H. The Role of the Federal Government in Assuring Access to Health Care. *Inquiry*. Fall 1986; 23:286-95.
- Dievler A. Legislative Update. *The Genetic Resource*. 1985-86; 2:33-5.
- Dresser RS, Boisaubin EV. Ethics, Law, and Nutritional Support. *Arch Intern Med*. 1985; 145:122-4.
- Durenberger. S 2403. U.S. Congressional Record. 1986. Elling RH. The Capitalist World-System and International Health. *Int J Health Serv*. 1981; 11:21-51.
- Farley PJ. Private Health Insurance In The United States. DHHS Publication No.(PHS)86-3406. September 1986; 1-106.
- Foets M, Berghmans F, Janssens L. The Primary Health Care Project in Belgium: A Survey on the Utilization of Health Services. *Soc Sci Med*. 1985; 20:181-90.
- Gardent H, Goujard J, Fardeau M, Crost M. Economics of the Diffusion of Prenatal Diagnosis by Amniocentesis, Part One: Epidemiologic, Medical, & Socioeconomic Bases. *Revue Epidemiol Sante Publique*. 1984; 32:88-96.
- Gardent M, Fardeau M, Lanoe JL, Kerleau M. Economics of the Diffusion of Prenatal Diagnosis by Amniocentesis, Part 2: Facilitating Decision Making in the Field of Publique Health: Toward an Optimal Difference *Revue Epidemiol Sante Publique*. 1984; 32:97-106.
- The Genetic Resource. An Updated Directory of Comprehensive Genetic Centers Within Massachusetts. *The Genetic Resource*. 1985-86; 2:45-6.
- The Genetic Resource. In Vitro Fertilization Programs in Massachusetts. *The Genetic Resource*. 1985-86; 2:4-7.

- Gostin L. A Moment in Human Development. Legal Protection, Ethical Standards and Social Policy on the Selective Non-Treatment of Handicapped Neonates. *Am J Law & Med.* 1985; 11:31-78.
- Griffin M. Emotional Aspects of Infertility: A Public Health Concern. *The Genetic Resource.* 1985-86; 2:1-4.
- Guyer B. Children in a Changing Health Care System. Department of Maternal and Child Health. Harvard University School of Public Health. Feb. 23, 1987; 1-39.
- Haworth JC, Miller JR, Scriver CR. Screening, counselling and treatment of hereditary metabolic disease; a survey of resource. *Can Med Assoc. J.* November 16, 1974; 3:1147-1150.
- Hibbard BM, Roberts CJ, Elder GH, et al. Can We Afford Screening for Neural Tube Defects? The South Wales Experience. *Brit Med J.* 1985; 290:293-5.
- Hines B. Health Policy on the Town Meeting Agenda. *Hastings Center Report.* 1985; 5-7.
- Hines BL. Oregon And American Health Decisions. U.S. Department of Health and Human Services. July 1985; 1-45.
- Hoft RH, Glaser RJ. The Problems and Benefits of Associating Academic Medical Centers with Health-Maintenance Organizations. *N Engl J Med.* 1982; 307:1681-9.
- Hospital Management Review. Cost Containment Policies Expected to Delay Technological Innovation. *Hosp Management Rev.* 1986; 5:7.
- Ignatieff M. The Needs of Strangers. An Essay on Privacy, Solidarity, and the Politics of Being Human. Viking Penguin Inc. 40 W. 23rd St. NY, NY. 1985; 1-3.
- Israel BA. Social Networks and Social Support: Implications for Natural Helper and Community Level Interventions. *Health Education Quarterly.* 1985; 12:65-80.
- Jobert B. Populism and Health Policy: The Case of Community Health Volunteers in India. *Soc Sci Med.* 1985; 20:1-28.
- Johns L, Anderson MD, Derzon RA. Selective Contracting in California: Experience in the Second Year. *Inquiry.* Winter 1985; 22:335-47.
- Jones D, Relman A. Visions of Medicine. *Massachusetts Med.* Mar/Apr 1986; 22-31.
- Kasper AS. Maternal Serum Alpha Fetoprotein Testing: Some Public Policy Considerations. *Women-Health.* 1981; 6:147-53.
- Kennedy, Hatch. Bill S.1793—Alternatives to Hospitalization for Medical Technology Dependent Children Act of 1985. 99th Congress, 1st Session. 1985; 11.
- Kletke PR, Davidson SM, Perloff JD, et al. The Extent of Physician Participation in Medicaid: A Comparison of Physician Estimates and Aggregated Patient Records. *Health Services Research.* Dec. 1985; 20:5:503-23.
- Kolata G. Genetic Screening Raises Questions for Employers and Insurers. *Science.* 1986; 232:317-9.
- Landsman RM. Letter to the Editor—Ethics, Law, and Nutritional Support. *Arch Intern Med.* 1985; 145:2130-1.
- Letter to the Editor. Bagshawe KD. How Much Can the NHS Afford to Spend to Save a Life or Avoid a Severe Disability? *Lancet.* 1985; 1:80.
- Letter to the Editor, MacGregor JE. How Much Can the NHS Afford to Spend to Save a Life or Avoid a Severe Disability? *Lancet.* 1985; 1:80.
- Letter to the Editor, Path M, Leck I. How Much Can the NHS Afford to Spend to Save a Life or Avoid a Severe Disability? *Lancet.* 1985; 1:80.
- Lister J. Shattuck Lecture-The Politics of Medicine in Britain and the United States. *N Engl J Med.* July 1986; 315:3:168-73.
- McDonald DD. Health Care and Cost Containment for the Homeless: Curricular Implications. *J Nursing Ed.* 1986; 25:261-4.
- Mehta L, Young ID. Attitudes of Asian Families to Genetic Counselling. *J Med Gen.* 1985; 22:413.
- Meltzer J. Reforming the Medicaid Program to Improve Access to Health Care Services. *Bull. N.Y. Acad. Med.* Jan/Feb 1986; 62:1:87-93.
- Miller ST, Vander Zwagg R, Joyner MB, et al. Evaluation of a Decentralized System for Chronic Disease Care: Seven Years of Observation. *Am J Publ Health.* 1980; 70:401-5.
- Moffatt MEK, Peddie M, Stulginskas J, et al. Health Care Delivery to Foster Children: A Study. *Health Soc Work.* 1985; 10:129-37.
- Moskop JC, Saldanha RL. The Baby Doe Rule: Still a Threat. *Hastings Center Report.* 1986; 8-14.
- Nolan T, Desmond K, Herlich R, et al. Knowledge of Cystic Fibrosis in Patients and Their Parents. *Pediatrics.* 1986; 77:229-35.
- Olszewski J. Survey Shows DRGs Affect Health Care Delivery to Seniors. *Michigan Medicine.* 1985; 402-3.
- O'Malley D, Schlossman S, Doty K. Insurance Marketing By the Health Profession. *American Hospital Association National Meeting.* Nov. 1984.
- Pappas N, McGraw M. Companies Revise Health Coverage. *Hartford Courant.* Aug 11, 1985; 1, A16-17.
- Passarge E, Vogel F. The Delivery of Genetic Counseling Services in Europe. *Human Genet.* 1980; 56:1-5.
- Pediatric News. Health Care Needs of Children Said to Have Fallen Through Third-Party Coverage Net. *Pediatric News.* 1986; 20:3.
- Pena JJ. Marketing: A Necessary Art Under DRGs. *Hosp Management Rev.* 1986; 5:6.
- Perrin JM, Ireys HT. The Organization of Services for Chronically Ill Children and Their Families. *Ped Clin N Am.* 1984; 31:235-57.

- Pinch WJ. Allocation of Scarce Resources. *Critical Care Nursing Dilemma*. Dimensions of Critical Care Nursing. 1985; 4:164-73
- Poland RL, Bollinger RO, Bedard MP, et al. Analysis of the Effects of Applying Federal Diagnosis-Related Grouping (DRG) Guidelines to a Population of High-Risk Newborn Infants. *Pediatrics*. 1985; 76:104-9.
- Pressley SA. Are Walk-In Clinics Good for Your Health? *Parade Magazine*. July 28, 1985; 8-9.
- Reeder CE, Nelson AA. The Differential Impact of Copayment on Drug Use in a Medicaid Population. *Inquiry*. Winter 1985; 22:396-403
- Rowley PT, Fisher L, Lipkin Jr. M. Incorporation of Screening and Genetic Counseling for Beta-Thalassemia Trait into Primary Health Care: Effects on Knowledge & Attitudes. *Birth Defects:Original Article Series*. 1982; 18:231-241.
- Royston E, Ferguson J. The Coverage of Maternity Care. A Critical Review of Available Information. *Wld Hlth Statist Quart*. 1985; 38:267-88.
- Sadovnick AD, Baird PA. A Cost-Benefit Analysis of Prenatal Diagnosis for Neural Tube Defects Selectively Offered to Relatives of Index Cases. *Am J Med Gen*. 1982; 12:63-73.
- Schlesinger M. On the Limits of Expanding Health Care Reform. *Chronic Care in Prepaid Settings*. *Hosp Management Rev*. 1986; 5:10
- Schofield S, Leibert S. Health Cost Management Survey—Fall 1983—Resource Manual. Business Coalition on Health. Hartford, Conn. 1983.
- Schultz M. A Feverish Health Care Industry. Treatment: Strong Doses of Cost-Containment. Prognosis. Pittsburgh. July 1985; pp43-49,76.
- Scott-Samuel A. Point of View Social Inequalities in Health: Back on the Agenda. *Lancet*. May 1986; 1084-6.
- Scriber CR, Laberge C, Clow CL, et al. Genetics and Medicine: An Evolving Relationship. *Science*. 1978; 200:946-52.
- Selle HF, Holmes DW, Ingbar ML. The Growing Demand for Midtrimester Amniocentesis: A Systems Approach to Forecasting the Need for Facilities. *AJPH*. 1979; 69:574-80.
- Sepe SJ, Marks JS, Oatley GP, et al. Genetic Services in the United States. *JAMA*. 1982; 248:1733-5.
- Siminovitch L, Banister P, Byles JA, et al. Genetic Services. The Ontario Council of Health. Toronto, Ontario. 1976.
- Sorenson JR. Clinics, Counselors, and Clients. *Birth Defects Original Article Series*. 1981; 17:431-50.
- Stephen R, Amato S. Council of Regional Networks for Genetic Services. Morgantown, WV: Department of Pediatrics, West Virginia University. 1985.
- Suslak L, Price DM, Desposito F. Transmitting Balanced Translocation Carrier Information Within Families: A Follow-Up Study. *Am J Med Gen*. 1985; 20:227-32.
- Winston WJ. Positioning the Long-Term and Senior Care Service in the Minds of the Medical Provider and Consumer. *Health Mark Q*. 1984; 1:51-67.
- Wrenn K. No Insurance, No Admission. *N Engl J Med*. 1985; 312:373-4.

## CATEGORY 2—CHRONIC CARE (LONG TERM CARE)

### A. Primary References

- Akhmeteli MA, Aledort LM, Alexaniants S, et al. Methods for the Detection of Hemophilia Carriers: A Memorandum. *Bulletin of the World Health Organization*. 1977; 55:675-702.
- Anlyan WG, Lipscomb J. The National Health Care Trust Plan: A Blueprint for Market and Long-Term Care Reform. *Health Aff*. 1985; 4:5-31.
- Bay KS, Leatt P, Stinson SM. A Patient-Classification System for Long-Term Care. *Medical Care*. 1982; 20:468-88.
- Bender AN. Diagnosis: Muscular Dystrophy. *Hospital Medicine*. 1984; 95:125.
- Black M. Handicapped Children in a Developing Nation—Bangladesh. *Am J Occup Ther*. 1977; 31:499-504.
- Bradshaw J, Lawton D. Utilization of the Family Fund. *Child: Care, Health and Development*. 1982; 8:226-237.
- Canam C. Talking About Cystic Fibrosis Within the Family—What Parents Need to Know. *Issues in Comprehensive Pediatric Nursing*. 1986; 9:167-78.
- Clare MD. Home Care of Infants and Children with Cardiac Disease. *Heart & Lung*. 1985; 14:218-22.
- Clochesy JM, Whittaker AA, Murdaugh CL. Hypoplastic Left Heart Syndrome: A Review and the Report of Two Cases. *Heart & Lung*. 1986; 15:23-8.
- Gin H, Larregain F. Legislation du Diabete (2e partie). *La Presse Medicale*. 1985; 14:1684-5.
- Glendon M. Teaching Harry What We'd Thought He Knew. *Nursing85*. 1985; 44-6.
- Kanthor H, Pless B, Satterwhite B, et al. Areas of Responsibility in the Health Care of Multiply Handicapped Children. *Pediatrics*. 1974; 54:779-85.
- Ma P, Piazza F. Cost of Treating Birth Defects in State Crippled Children's Services, 1975. *Public Health Reports*. 1979; 94:420-4.
- Markova I, Forbes CD, Inwood M. The Consumers' Views of Genetic Counseling of Hemophilia. *Am J Med Gen*. 1984; 17:741-752.
- McNamara DG, Latson LA. Long-Term Follow-Up of Patients With Malformations for Which Definitive Surgical Repair Has Been Available for 25 Years or More. *Am J Cardiol*. 1982; 50:560-8.
- Meiners MR. The State of the Art in Long-Term Care Insurance. U.S. Department of Health and Human Services. April 1984; 1-34.
- Meiners MR, Coffey RM. Hospital DRGs and the Need for Long-Term Care Services: An Empirical Analysis. *Health Services Research*. August 1985; 20;3:359-84.
- Meiners MR, Trapnell GR. Long-term Care Insurance—Premium Estimates for Prototype Policies. *Medical Care*. Oct. 1984; 22;10:901-11.
- Miller ST, Vander Zwagg R, Joyner MB, et al. Evaluation of a Decentralized System for Chronic Disease Care: Seven Years of Observation. *Am J Publ Health*. 1980; 70:401-5.
- Olsen LJ. Letters to the Editor—Long Term Care Regulations. *Del Med J*. 1985; 57:669.
- Orsini A. Aspects Medico-Sociaux des Hemoglobinoses. *Arch Franc Ped*. 1977; 34:393-8.
- Perloff JK. The UCLA Adult Congenital Heart Disease Program. *Am J Cardiol*. 1986; 57:1190-2.
- Perrin JM, Ireys HT. The Organization of Services for Chronically Ill Children and Their Families. *Ped Clin N Am*. 1984; 31:235-57.
- Phillips S, Bohannon WE, Gayton WF, et al. Parent Interview Findings Regarding the Impact of Cystic Fibrosis on Families. *JDBP*. 1985; 6:122-7.
- Rice JA, Taylor S. Assessing the Market for Long-Term Care Services. *Healthcare Financial Management*. 1984; 38:32-6,42-6.
- Rosenthal A. Care of the Postoperative Child and Adolescent with Congenital Heart Disease. *Advances in Pediatrics*. 1983; 30:131-67.
- Rubin RJ. Financing Long -Term Care. *N Engl J Med*. 1982; 306:P1494.
- Ruchlin HS, Morris JN, Eggert GM. Management and Financing of Long Term Care Services. *N Engl J Med*. 1982; 306:101-5.
- Schlesinger M. On the Limits of Expanding Health Care Reform: Chronic Care in Prepaid Settings. *Hosp Management Rev*. 1986; 5:10.
- Seward ML. Measuring Health Care Utilization and Costs During and After Medical Rehabilitation. Annual Meetings of Natl. Assoc. of Rehab. Research & Training Centers. Wash. D.C. Presentation. 1985; P1.
- Sinnock P, Bauer DW. Reimbursement Issues in Diabetes. *Diabetes Care*. 1984; 7:291-6.
- Storhaug K. Aspects of Living Conditions Among Groups of Disabled Children and Their Families in Norway: Family Situation, Mothers' Health, Financial Assistance. *Soc Sci Med*. 1983; 17:1837-45.
- Ullmann SG. The Impact of Quality on Cost in the Provision of Long-Term Care. *Inquiry*. 1985; 22:293-302.
- Univ. Affiliated Fac., Rose F. Kennedy Ctr. Albert Einstein Coll. of Med. Health Financing for Chronically Ill & Disabled Children: Developing the Data Base & Policy Proposals. Yeshiva Univ, Ben. Cardozo Sch. of Law SA. Einstein Col. of Med. 1984; 1-25.
- Walters I, Baysinger M, Echanan I, et al. Complications of Sickle Cell Disease. *Nursing Clin of N America*. 1983; 18:139-84.
- Watkins PJ. ABC of Diabetes—Practical Problems. *Brit Med J*. 1982; 285:866-7.

Winston WJ. Positioning the Long-Term and Senior Care Service in the Minds of the Medical Provider and Consumer. *Health Mark Q.* 1984; 1:51-67.

#### B. Secondary References— Chronic Care (Long Term Care)

- Abuelo D, Bowers GB, Haddad V. Letter to the Editor. Genetic Counseling for Low Maternal Serum Alpha-Fetoprotein. *Am J Obstet Gynecol.* 1984; 151:147.
- Bosso JA, Stephenson SEH, Herbst JJ. Feasibility and Cost Savings of Intravenous Administration of Aminoglycosides in Outpatients with Cystic Fibrosis. *Drug Intell & Clin Pharmacy.* 1985; 19:52-4.
- Curtiss FR. Recent Developments in Federal Reimbursement for Home Health Care. *Am J Hosp Pharm.* 1986; 43:132-9.
- Health Care Financing Administration. Federal Initiatives on Home Care Under the Medicaid Program. *Coalition Quarterly.* 1985; 4:10-11.
- Hudson RB. A Block Grant to the States for Long-Term Care. *J Health Polit, Polic & Law.* 1981; 6:9-28.
- Krischer JP, Cook BA. State and Federal Expenditures on Medicaid Eligible Chronically Ill Children in Rural Florida. *J Chron Dis.* 1985; 38:11:951-6.
- Levine C. The Case of Baby Jane Doe. *The Hastings Center Report.* 1984; 10-19.
- Lis EF. Children's Home Health Network of Illinois (CHHNI). Personal Communication. Univ of IL at Chicago. 1985; 1-2.
- Ma P, Piazza F. Cost of Treating Birth Defects in State Crippled Children's Services, 1975. *Publ Health Rep.* 1979; 94:420-4.
- Merowitz M. Some Ethical Dilemmas in Empathic Provision of Long-term Clinical Care. *J. Geriatr. Psychiatry.* 1985; 18:1:75-9.
- Moskop JC, Saldanha RL. The Baby Doe Rule: Still a Threat. *Hastings Center Report.* 1986; 16:8-14.
- Muldoon J, Lewis B. Results from Research Project Show DRGs Unreliable for Measuring Severity of Children's Illnesses. *The Natl Assoc of Children's Hosp & Related Inst, Inc, NACHRI Reports.* 1985; 1-4.
- National Clearing House For Drug Abuse Information. Report Series 35, Issue A. U.S. Department of Health, Education, and Welfare. August 1975; 1-39.
- Newacheck PW. Reimbursement for Chronically Ill Children (SPRANS). Personal Communication, Univ. of Calif, San Francisco. 1985; 1-24.
- Policy Analysis I. Children's Hospital's Case Mix Classification System Project. Phase I: Critique of DRGs Across Hospital Settings. *National Assoc. of Children's Hosp. & Related Inst. Inc.* 1985; 1-30.
- Scull A. Deinstitutionalization and Public Policy. *Soc Sci Med.* 1985; 20:545-52.
- Silber F. HMOs and Care of the Chronically Ill. *Hospital Practice.* June 1986; 13.
- Starfield B, Dutton D. Care, Costs, and Health: Reactions to and Reinterpretation of the Rand Findings. *Pediatrics.* 1985; 76:614-21.
- Vogt BL, Zuber C, Librizzi RJ. Time Intensity of Patient Calls to a Teratogen Information Program. *Teratology Society 26th Annual Meeting.* July 1986; P95C.
- Votava KM, Cleveland T, Hiltunen K. Home Care of the Patient Dependent on Mechanical Ventilation: Home Care Policy Development and Goal Setting Using Outcome Criteria for Quality Assurance. *Home Health Care Nurse.* 1985; 3:2:18-25.
- Weil WB. The Baby Doe Regulations: Another View of Change. *Hastings Center Report.* 1986; 16:12-3.
- Whitcomb ME. Health Care For The Poor; A Public-Policy Imperative. *The New Engl J of Med.* Nov. 1986; 315:19:1220-22.
- Woolfe T. Medicine's Goal Overshadowed by Technology. *Hartford Courant.* November 17, 1985; B1-B3.
- Zwaag RV, Mason WB, Joyner B, Runyan Jr. JW. Cost of Chronic Disease Care. *J Chron Dis.* 1980; 33:713-20.



## CATEGORY 3—CONSUMER ISSUES

### A. Primary References

- Adler J. Birth Defects, Every Parent's Nightmare. *Newsweek*. March 16, 1987; 57-66.
- Brink SD. Healthcare in the 1990s: A Buyer's Market. *Hosp Management Rev*. 1986; 4.
- Cassak D. Extended Product Line—Preparing for the Consumer Revolution in Health Care. *Hosp Management Rev*. 1986; 5:1.
- Clayton BE. Problems Affecting the Community—Population Screening. *J Clin Path*. 8:145-9.
- Davies BL. Decision Making in Prenatal Genetic Diagnosis. *Issues in Health Care of Women*. 1983; 4:69-76.
- Faden RR, Chwalow AJ, Orel-Crosby E, et al. What Participants Understand About a Maternal Serum Alpha-Fetoprotein Screening Program. *AJPH*. 1985; 75:1381-4.
- Fibison WJ, Davies BL. Dilemmas in Prenatal Diagnosis: A Case Study. *Issues in Health Care of Women*. 1983; 4:57-67.
- Hook EB, Schreinemachers DM. Trends in Utilization of Prenatal Cytogenetic Diagnosis by New York State Residents in 1979 and 1980. *AJPH*. 1983; 73:198-202.
- Leslie LA, Swider SM. Changing Factors and Changing Needs in Women's Health Care. *Nurs Clin N Am*. 1986; 21:111-23.
- Marquis MS. Consumers' Knowledge about Their Health Insurance Coverage. *Health Care Financing Review*. 1983; 5:65-80.
- Moffatt MEK, Peddie M, Stulginskis J, et al. Health Care Delivery to Foster Children: A Study. *Health Soc Work*. 1985; 10:129-37.
- Nolan T, Desmond K, Herlich R, et al. Knowledge of Cystic Fibrosis in Patients and Their Parents. *Pediatrics*. 1986; 77:229-35.
- Pena JJ. Marketing: A Necessary Art Under DRGs. *Hosp Management*. 1986; 5:6.
- President's Commission for the Study of Ethical Problems in Medicine, and Biomedical and Behavioral Research. The Setting of the Report. Screening and Counseling for Genetic Conditions. 1983; U.S. Government Printing Office:1-5-41.
- Rice N, Doherty R. Reflections on Prenatal Diagnosis: The Consumer's Views. *Soc Work Health Care*. 1982; 8:47-57.
- Sadovnick AD, Baird PA. Reproductive Counselling for Multiple Sclerosis Patients. *Am J Med Genet*. 1985; 20:349-54.
- Vurnig P. Long-Gap Esophageal Atresia—Prenatal Diagnosis of Congenital Malformations. *Progress in Pediatric Surgery*. 1986; 19:197-202.
- Wertz DC, Sorenson JR. Client Reactions to Genetic Counseling: Self-Reports of Influence. *Clin Genet*. 1986; 30:494-502.

## **B. Secondary References—Consumer Issues**

- B. skin J. Prenatal Testing for Tay-Sachs Disease in the Light of Jewish Views Regarding Abortion. *Issues in Health Care of Women*. 1983; 4:141-56.
- Beeson D, Douglas R, Lunsford TF. Prenatal Diagnosis of Fetal Disorders—Part II: Issues and Implications. *Birth*. 1983; 10:233-42.
- Black RB, Furlong R. Impact of Prenatal Diagnosis in Families. *Soc Work Health Care*. 1984;37-50.
- Blendon RJ. Health Policy Choices for the 1990s. *Hosp Management Rev*. 1986; 5:10.
- Butler BB. Caring for the Family of an Infant with a Genetic Disorder. *Perinatal Press*. 1984; 8:55-7.
- Butler WJ. Ethics and Patients' Rights. *Consultant*. 1986; 87-92.
- Dobson J, Koch R, Williamson M, et al. Cognitive Development and Dietary Therapy in Phenylketonuric Children. *N Eng J Med*. 1968; 278:1142-4.
- Dorner W. Clearing Up the Public's Misconceptions about Health Care. *Ohio State Med J*. July 1985; 81:7:463,65,67.
- Ershkowitz M. Human Service Delivery Policy-Making in American Cities: The Case of Genetic Disease Trait-Testing Programs. *J Health Hum Res Admin*. 1980; 3:204-28.
- Harris RL. Information, Risk and Professional Ethics. *Am Ind Hyg Assoc J*. 1986; 47:67-71.
- Markova I, Forbes CD, Aledort LM, et al. A Comparison of the Availability and Content of Genetic Counseling as Perceived by Hemophilic Men and Carriers in the U.S.A., Canada, Scotland, and Greece. *Am J Med Gen*. 1986; 24:7-21.
- Mennuti MT. Teratology and Genetic Counseling in the Diabetic Pregnancy. *Clin Obstet and Gyn*. 1985; 28:486-95.
- Middleton GF, Lass NJ, Starr P, et al. Survey of Public Awareness and Knowledge of Cleft Palate. *Cleft Palate J*. 1986; 23:58-62.
- Roghmman KJ, Doherty RA. Reassurance Through Prenatal Diagnosis and Willingness to Bear Children After Age 35. *AJPH*. 1983; 73:760-2.
- Thurmon TF. Practical Concepts About Risks and Risk Management. *Consultant*. 1985; 43-56.
- Waddill GC. Genetic Screening: A Medicolegal Time Bomb? *Med Lab Observer*. 1983; 55-8.



## CATEGORY 4—COST CONTAINMENT/REIMBURSEMENT

### A. Primary References

- Abuelo D, Bowers GB, Haddad V. Letter to the Editor. Genetic Counseling for Low Maternal Serum Alpha-Fetoprotein. *Am J Obstet Gynecol.* 1984; 151:147.
- Baker PA. Medicine and Economics—Cost Benefit Analysis of Screening Spina Bifida. *NZ Med J.* 1981; 93:386-9.
- Banta D. On "A Decline in Earning Losses Associated With a Community-Based Cardiovascular Disease Prevention Project." *Med Care.* 1982; 20:661-2.
- Banta D. Computer Tomography: Cost Containment Misdirected. *Am J Publ Health.* 1980; 70:215-6.
- Barden HS, Kessel R, Schuett VE. The Costs and Benefits of Screening for PKU in Wisconsin. *Social Biology.* 31;1-2:1-17.
- Battistella RM, Weil TP. Procompetitive Health Policy: Benefits and Perils. *Hosp Management Rev.* 1986; 5:11.
- Benson Gold R, Kenney AM. Paying for Maternity Care. *Family Planning Perspectives.* May/June 1985; 17;3:103-11.
- Bergler JH. Options for Consideration in the Development of Reimbursement for Genetic Services. Washington, D.C.: Department of Health Care Administration, George Washington University. 1979; 1-21.
- Bernhardt BA, Weiner J, Foster EC, et al. A Time Analysis of Clinical Genetics Services. American Society of Human Genetics 37th Annual Meeting. Nov. 1986; A51.
- Bosso JA, Stephenson SEH, Herbst JJ. Feasibility and Cost Savings of Intravenous Administration of Aminoglycosides in Outpatients with Cystic Fibrosis. *Drug Intell & Clin Pharmacy.* 1985; 19:52-4.
- Bradshaw K. Children's Hospital Association Awarded Grants for Case Mix Payment Project. *NACHRI Reports.* July 1984.
- Bryce RL, Pritchard RC. The Cost of Routine Antenatal Screening for Syphilis. *Aust NZ J Obstet Gynec.* 1981; 21:211-13.
- Buchanan RJ, Minor JD. Legal Aspects of Health Care Reimbursement. *J Legal Med.* 1985; 6:553-62.
- Bush JW, Chen MM, Patrick DL. Health Status Index in Cost Effectiveness: Analysis of PKU Program. *Health Status Indexes.* 1973; Hospital Research and Educational Trust, Chicago. 173-208.
- Cable RG, Saxon P, Rickles F, Katz AJ. Home shipment of Coagulation Factor Concentrated by a Regional Blood Center. Analysis of 5 year's Experience. *American National Red Cross.* 1984; 1-28.
- Camerson JM. The Indirect Costs of Graduate Medical Education. *N Engl J Med.* 1985; 321:1233-38.
- Caper P, Blumenthal D. What Price Cost Control? *N Engl J Med.* 1983; 308:242-44.
- Carter PE, Pearn JH, Bell J, Martin N, Anderson AG. Survival in trisomy 18. Life tables for use in genetic counselling and clinical pediatrics. *Clinical Genetics.* 1985; 27:59-61.
- Chamberlain J. The Benefits and Costs of Prenatal Diagnosis (Editorial). *Revue Epidemiol Sante Publique.* 1984; 32:85-87.
- Cohen DI. The Use of Prenatal Cytogenetic Diagnosis: A Comparison of Rates in Prepaid Group Practices and the General Population. *Medical Care.* 1980; 18:513-19.
- Connecticut General Assembly. Committee Bill LCO Bo. 212—An Act Establishing a Prospective Payment System for Hospitals. Personal Communication. Hartford, CT. 1984; 1-14.
- The Connecticut Hospital Association. Hospital Costs and Government Regulation. The Connecticut Experience. Connecticut Hospital Association. 1985; 21.
- The Connecticut Hospital Association. The Connecticut Hospital Association 1985-86 Legislative Directory. The Connecticut Hospital Association. 1985.
- Copeland NR. The Impact of DRG's in Hospitals in Delaware. *Del Med J.* 1986; 58:96-8.
- Czeizel A, Metneki J. Recurrence Risk After Neural Tube Defects in a Genetic Counseling Clinic. *J Med Gen.* 1984; 21:413-16.
- Czeizel A, Sankaranarayanan K. The load of genetic and partially genetic disorders in man. *Mutation Research.* 128. 1984; 73-103.
- Dagenais DL, Courville L, Dagenais MG. A Cost-Benefit Analysis of the Quebec Network of Genetic Medicine. *Soc Sci Med.* 1985; 20:601-7.
- The Division of Medical Genetics J.H.M.I. Economic Aspects of Clinical Genetics Services. Genetic Disease Services Branch, Division of Maternal and Child Health. May 1-2, 1986; 1-14.
- Doubilet P, Wainstein MC, McNeil BJ. Use and Misuse of the Term "Cost Effective" in Medicine. *N Engl J Med.* 1986; 314:253-55.
- Farley DE. Competition Among Hospitals: Market Structure and Its Relation to Utilization, Costs and Financial Position. U.S. Department of Health and Human Services. Aug. 1985; 1-22.
- Fein R. Effects of Cost Sharing in Health Insurance. *N Engl J Med.* 1981; 305:1526-28.
- Freire-Maia N. Effects of Consanguineous Marriages on Morbidity and Preconscious Mortality: Genetic Counseling. *Am J Med Gen.* 1984; 18:401-6.
- Ginsburg PB, Sloan FA. Hospital Cost Shifting. *N Engl J Med.* 1984; 310:893-98.

- Gordon T, DeAngelis C, Peterson R. Capitation Reimbursement for Pediatric Primary Care. *Pediatrics*. 1986; 77:29-34. Grace HJ. Prenatal Screening for Neural Tube Defects in South Africa-an Assessment. *So Af Med J*. 1981; 60:324-9.
- Gray BH, McNerney WJ. For-Profit Enterprise in Health Care: The Institute of Medicine Study. *N Engl J Med*. June 1986; 314:23:1523-28.
- Greenberg DS. Washington Report-Reimbursement Wars. *N Engl J Med*. 1980; 303:538-40.
- Green J. Detecting the Hypersusceptible Worker: Genetics and Politics in Industrial Medicine. *International J of Health Services*. 1983; 13:247-64.
- Greenstein RM. Connecticut Reimbursement Policy. Personal Communication, RM Greenstein. 1982; 2.
- Grossman LK, Holtzman NA, Charney E, Schwartz AD. Neonatal Screening and Genetic Counseling for Sickle Cell Trait. *Am J Disease Children*. March 1985; 139:241-244.
- Hagard S, Carter F, Milne RG. Screening for Spina Bifida Cystica. A Cost-Benefit Analysis. *Brit J Preb Soc Med*. 1976; 30:40-53.
- Hamme JM, Tillman E. DRGs and Long Term Care: Part One. *Contemp Adm Long Term Care*. 1984; 7:25-6.
- Haworth JC, Miller JR, Scriver CR. Screening, counselling and treatment of hereditary metabolic disease; a survey of resource. *Can Med Assoc. J*. November 16, 1974; 3:1147-50.
- Henderson JB. Measuring the benefits of screening for open neural tube defects. *J Epi & Comm Health*. 1982; 36:214-19.
- Himmelstein DU, Woolhandler S. Cost Without Benefit: Administrative Waste in U.S. Health Care. *N Engl J Med*. Feb. 1986; 314:7:441-45.
- Holt LH. DRGs (Diagnostic Related Groups): The Doctors' Dilemma. *Perspect Biol and Med*. 1986; 29:219-26.
- Holzgreve B, Holzgreve W, Golbus MS. The relevance of preamniocentesis pedigree analysis and genetic counseling. *Clinical Genetics*. 1983; 24:429-33.
- Hook EB. Alpha-Fetoprotein and Karyotyping of Amniotic Fluid. *Lancet*. 1981; 1:729.
- Horn SD, Horn RA, Sharkey PD, et al. Misclassification Problems in Diagnosis-Related Groups. Cystic Fibrosis An Example. *N Engl J Med*. 1986; 314:484-87.
- Hospital Management Review. Can Hospitals Survive Under PPS and Maintain Quality of Care? *Hosp Management Rev*. 1986; 5.
- Hospital Management Review. Cost Containment Policies Expected to Delay Technological Innovation. *Hosp Management Rev*. 1986; 5:7.
- Iglehart JK. Health Policy Report: Early Experience With Prospective Payment of Hospitals. *N Engl J Med*. May 1986; 314:22:1460-64.
- International Medical News Service. Prospective Payment Based on Time May Best Control Care Costs. *Pediatric News*. Jan. 1985; 19:5.
- Isaacs JC, Seline NE. Net Patient Revenue at University Owned Teaching Hospitals. FY 1982. Datagram, AAMC Department of Teaching Hospitals, Washington D.C. 1982.
- Jacklin M. Lawmakers Establish Cost Controls. *Hartford Courant*. Apr. 24, 1985; B1,4.
- Jeddeloh NP, Bierig JR, Allen HS. Implementing DRGs: Developing Effective Strategies (Based on the Final 1984 Regulations). Center for Educational Development. 1984; (Videotape).
- Jeter KF. After Discharge: The Early and Later Health Needs of Children with Multiple Birth Defects, Part III. *Infect Control Urol Care*. 1982; 7:3-5.
- Jones D, Relman A. Visions of Medicine. *Massachusetts Med*. Mar/Apr 1986; 22-31.
- Kahkonen DM. DRG Impact on Medical Care. *Michigan Medicine*. 1985; 403.
- Kaplan G. The Blue Cross and Blue Shield Association's Genetic Services Benefit Study. *Birth Defects*. 1984; 20:6:53-57.
- Kloza EM. Third Party Payment for Genetic Services. *Maine Assoc, Hu Gen News Bulletin*. 1983; 6:1-2.
- Knapp RE. The development of Outpatient DRGs. *J Ambulatory Care Management*. May 1983; 1-11.
- Knight PJ, Clatworthy Jr. HW. Screening for Latent Malformations: Cost Effectiveness in Neonates with Correctable Anomalies. *J Ped Surg*. 1982; 17:123-9.
- Kolata G. Genetic Screening Raises Questions for Employers and Insurers. *Science*. 1986; 232:317-9.
- Lagoe RJ, Milliren JW, Baader MJ. Impact of Selected Diagnosis-Related Groups on Regional Neonatal Care. *Pediatrics*. 1986; 77:627-32.
- Lane LF. Understanding Long Term Care Policy and the Consequences of Reimbursement. *Pride Inst J Long Term Health Care*. 1983; 2:7-20.
- Leichter SB. Third Party Reimbursement: An Alternate Approach. *The Diabetes Educator*. Fall 1983; 32-3.
- Leichtman LG, Say B, Caldwell JG. Patients in a Clinic for Children With Multiple Handicaps: A Retrospective Diagnostic Evaluation. *South Med J*. 1980; 73:1221-5.
- Lenke RR, Levy HL. Maternal Phenylketonuria and Hyperphenylalaninemia—An International Survey of the Outcome of Untreated and Treated Pregnancies. *N Eng J Med*. 1980; 303:1202-8.
- Levey S, Hesse DD. Sounding Board—Bottom-Line Health Care? *N Engl J Med*. 1985; 312:644-47.

- Leyland AF, Carroll MY, Kaplan GN. Health Services Foundation. Final Report Genetics Services Benefit Study. BC & BS, 676 N. St. Clair St. Chicago IL 60611. 1983; 1-87.
- Lubs ML. Letter to the Editor: Cost Benefit Analysis in Genetic Disorders. *Am J Med Gen.* 1980; 6:331-32.
- Ma P, Piazza F. Cost of Treating Birth Defects in State Crippled Children's Services, 1975. *Publ Health Rep.* 1979; 94:420-4.
- Massachusetts Department of Public Health. Cost-Benefit Analysis of Newborn Screening for Metabolic Disorders. *N Eng J Med.* 1974; 291:1414-6.
- May JJ. Impact of Diagnosis Related Groups on Medical Practice. *Am J Cardiol.* 1985; 56:16C-26C.
- McDonald DD. Health Care and Cost Containment for the Homeless: Curricular Implications. *J Nursing Ed.* 1986; 25:261-4.
- McMenamin P. Future Research and Policy Directions in Physician Reimbursement. *Health Care Financing Review.* Spring 1981; 61-75.
- Meyers TL. Amniocentesis Cost Study. Johnson City, TN: Dept. of Pediatrics, East Tennessee State University. 1980.
- Mid-Atlantic Regional Human Genetic Network. Minimum Data Set. Mid-Atlantic Regional Human Genetic Network.
- Muldoon J, Lewis L. Results from Research Project Show DRGs Unreliable for Measuring Severity of Children's Illnesses. *The Natl Assoc of Children's Hosp & Related Inst, Inc, NACHRI Reports.* 1985; 1-4.
- Nelson WB, Swint JM, Caskey CT. An Economic Evaluation of a Genetic Screening Program for Tay-Sachs Disease. *Am J Hum Genet.* 1978; 30:160-6.
- Newhouse JP, Manning WG, Morris CN, et al. Some Interim Results from a Controlled Trial of Cost Sharing in Health Insurance. *N Engl J Med.* 1981; 305:1501-7.
- Olszewski J. Survey Shows DRGs Affect Health Care Delivery to Seniors. *Michigan Medicine.* 1985; 402-3.
- Pediatric News. Reimbursement Plan for Neonate ICU Care. *Pediatric News.* July 1985; 12.
- Pediatric News. HCFA Weighs Cost Trimming Options for Physicians. *Pediatric News.* Aug 1985; 19:13.
- Petersdorf RG. Current and Future Directions for Hospital and Physician Reimbursement-Effect on the Academic Medical Center. *JAMA.* May 3, 1985; 253:17:2543-48.
- Poland RL, Bollinger PO, Bedard MP, et al. Analysis of the Effects of Applying Federal Diagnosis-Related Grouping (DRG) Guidelines to a Population of High-Risk Newborn Infants. *Pediatrics.* 1985; 76:104-9.
- Policy Analysis I. Children's Hospital's Case Mix Classification System Project. Phase I: Critique of DRGs Across Hospital Settings. *National Assoc. of Children's Hosp. & Related Inst. Inc.* 1985; 1-30.
- Pressley SA. Are Walk-In Clinics Good for Your Health? *Parade Magazine.* July 28, 1985; 8-9.
- Reiss JB. Primer: The Purchase and Sale of Health Care under a Prospective Payment System. Personal Communication. Dechert Price & Rhoads, Philadelphia. 1983; 1-33.
- Relman AS. Who Will Pay for Medical Education in Our Teaching Hospitals? *Science.* Oct 5, 1984; 226:20-3.
- Richardson D, Rosoff A, McMenamin JP. Referral Practices and Health Care Costs—The Dilemma of High Risk Obstetrics. *J Legal Med.* 1985; 6:427-64.
- Rollnick BR. A Time Analysis of a Genetic Counseling Delivery System. *Birth Defects.* 1984; 20:6:208-12.
- Rowley PT, Lipkin M, Fisher L. Screening and Genetic Counseling for Beta-Thalassemia Trait in a Population Unselected for Incomparision of Three Counseling Methods. *Am J Hum Genetics.* 1984; 36:677-689.
- Sadovnick AD, Baird PA. A Cost-Benefit Analysis of a Population Screening Program for Neural Tube Defects. *Prenatal Diagnosis.* 1983; 3:117-26.
- Sadovnick AD, Baird PA. A Cost-Benefit Analysis of Prenatal Diagnosis for Neural Tube Defects Selectively Offered to Relatives of Index Cases. *Am J Med Gen.* 1982; 12:63-73.
- Sadovnick AD, Baird PA. Maternal Age-Specific Costs of Detecting Down Syndrome and Neural Tube Defects. *Canadian J of Public Health.* 1982; 73:248-50.
- Sadovnick AD, Baird PA. A Cost-Benefit Analysis of Prenatal Detection of Down Syndrome and Neural Tube Defects in Older Mothers. *Am J Med Gen.* 1981; 10:367-78.
- Scheffler RM, Paringer L. A Review of the Economic Evidence on Prevention. *Med Care.* 1980; 18:473-84.
- Schofield S. Health Cost Management Survey. Personal Communication. Business Coalition on Health, Hartford, CT. 1985; 1-11.
- Schofield S, Leibert S. Health Cost Management Survey—Fall 1983—Resource Manual. Business Coalition on Health. Hartford, Conn. 1983.
- Schultz M. A Feverish Health Care Industry. Treatment: Strong Doses of Cost-Containment. Prognosis. *Pittsburgh.* July 1985; 43-49,76.
- Schwartz WB, Newhouse JP, Williams AP. Is the Teaching Hospital an Endangered Species? *N Engl J Med.* 1985; 313:157-62.

- Schwartz W, Joskow P. Medical Efficiency Versus Economic Efficiency: A Conflict in Values. *N Engl J Med*. December 28, 1978; 299:6:1462-64.
- Select Committee on Children, Youth, and Families. Opportunities for Success: Cost-Effective Programs for Children. House of Representatives, 99th Congress 1st Session. 1985; 1-34.
- Sinn JL. Sounding Board—The Hospital Trustees' Dilemma—To Sell or Not to Sell? *N Engl J Med*. 1985; 313:181.
- Smith PS, Keyes NC, Forman EN. Socioeconomic Evaluation of a State-Funded Comprehensive Hemophilia-Care Program. *N Engl J Med*. 1982; 306:575-9.
- Somer AR. Why Not Try Preventing Illness as a Way of Controlling Medicare Costs? *N Engl J Med*. 1984; 311:853-856.
- Somers AR. Long-Term Care for the Elderly and Disabled—A New Health Priority. *N Engl J Med*. 1982; 307:221-26.
- Spivey BE. The Relation Between Hospital Management and Medical Staff under a Prospective-Payment System. *N Engl J Med*. 1984; 310:984-86.
- Starfield B, Dutton D. Care, Costs, and Health: Reactions to and Reinterpretation of the Rand Findings. *Pediatrics*. 1985; 76:614-21.
- Stern RS, Epstein AM. Institutional Responses to Prospective Payment Based on Diagnosis-Related Groups—Implications for Cost, Quality, and Access. *N Engl J Med*. 1985; 312:621-27.
- Swint JM, Shapiro JM, Corson VI, et al. The Economic Returns to Community and Hospital Screening Programs for a Genetic Disease. *Preventive Med*. 1979; 8:463-70.
- Takenaga N, Kai I, Ohi G. Evaluation of Three Cervical Cancer Detection Programs in Japan With Special Reference to Cost-Benefit Analysis. *Cancer*. 1985; 55:2514-19.
- Tanner DJ. Health Care Cost-Containment in a Changing Health Care World. *Drug Intell Clin Pharm*. 1985; 19:291-2.
- Thallner KA. Prospective Payment System—Preclusion of Review of Hospital Base Year Cost Calculations. *J Legal Med*. 1985; 6:509-43.
- U.S. Dept. of HEW. Third Party Reimbursement-Basic Concepts Title XX—Social Services Funding. Natl. Clearinghouse for Drug Abuse Information Report Series 35 Issue A. Wash. D.C. Gov. Printing Offices. 1975.
- Walker DB, Feldman A, Vohr BR, Oh W. Cost-Benefit Analysis of Neonatal Intensive Care for Infants Weighing Less Than 1000 Grams at Birth. *Pediatrics*. 1984; 74:20-25.
- Wallack S. Where Are New Resources for Financing Long Term Care? *Pride Inst J Long Term Health Care*. 1983; 2:21-40.
- Weinstein M, Stason W. Foundations of Cost-Effectiveness Analysis for Health and Medical Practices. *N Engl J Med*. March 31, 1977; 716-21.
- Williams L. HCFA Examines 'RUGs' for Long Term Care Reimbursement Plan. *Today's Nurs Home*. 1983; 4:1,7.
- Wood AP. States Moving in Many Directions to Contain Health Costs. *Pediatric News*. March 1985; 19:69.
- Wood AP. Govt. Evaluation Disparate Types of Reimbursement. *Pediatric News*. Dec. 1984; 18:3.
- Wright ML, Elsas II LJ. Application of Benefit-to-Cost Analysis to an X-linked Recessive Cardiac and Humero-peroneal Neuromuscular Disease. *Am J Med Gen*. 1980; 6:315-29.
- Zwaag RV, Mason WB, Joyner B, Runyan Jr. JW. Cost of Chronic Disease Care. *J Chron Dis*. 1980; 33:713-20.

## B. Secondary References—Cost Containment/Reimbursement

- American Hospital Association. The Changing American Hospital. American Hospital Association. Chicago, Illinois.
- Anderson GF, Studnicki J. Insurers Competing with Providers. *Hospitals*. Dec 1, 1985; 64-6.
- Associated Press. Blue Cross May Not Deserve Tax Break, Auditors Report. *Hartford Courant*. July 28, 1986.
- Austin G. Child Health-Care Financing and Competition. *N Engl J Med*. 1984; 311:1117-1120.
- Baldwin MF. Boston HMOs Ready for Stepped-up Battle. *Modern Healthcare*. May 10, 1985; 42-6.
- Banta D. Technology—Review of Medical Technology Policies Shows Need, Opportunities for Changes. *Hospitals*. Apr. 1, 1982; 87-90.
- Beadle CE. Saving the FSA/Flex' can—and should—survive tax changes. *Business Insurance*. April 1, 1985; P25-26.
- Benn PA, Hsu LYF, Carlson A, et al. The Centralized Prenatal Genetics Screening Program of New York City III: The First 7,000 Cases. *Am J Med Genet*. 1985; 20:369-84.
- Berger LR. Abortions in America: The Effects of Restrictive Funding. *N Engl J Med*. 1978; 298:1474-7.
- Bernstein A. What Compensation for an Unwanted Life? *Hospitals*. Dec. 1984; 58:90.
- Briard ML, Kaplan J, Merrer ML, et al. Impact Du Conseil Genetique Sur La Fecondite des Couples. *J Genet Hum*. 1984; 32:257-63.
- Bunker JP, Fowles JJ, Schaffarzick R. Evaluation of Medical-Technology Strategies- Effects of Coverage and Reimbursement (First of Two Parts). *N Engl J Med*. 1982; 306:620-24.
- Chakravarti A, Buetow KH. A Strategy for Using Multiple Linked Markers for Genetic Counseling. *Am J Hum Gen*. 1985; 37:984-97.
- Connecticut General Assembly. Committee Bill LCO Bo. 212—An Act Establishing a Prospective Payment System for Hospitals. Personal Communication. Hartford, C. : 1984; pl-14.
- Cowchock S, Jackson L. Use of Alpha-Fetoprotein for Diagnosis of Neural Tube and Other Anomalies. *Clin Obstet Gynaecol*. 1980; 7:83-102.
- Cray E. The "Wrongful Life" Dilemma. *California Lawyer*. September 1982; 52:6:53-55;58-59;96-98.
- Cromwell J, Burstein P. Physician losses from Medicare and Medicaid discounts: How real are they? *Health Care Financing Review*. Summer 1985; 6:4:51-68.
- Dagenais DL, Courville L, Dagenais MG. A Cost-Benefit Analysis of the Quebec Network of Genetic Medicine. *Soc Sci Med*. 1985; 20:601-7.
- Daniels N, Miller FH, Miller GAH. Why Saying No to Patients in the United States is so Hard: Cost Containment, Justice, and Provider Autonomy. *N Engl J Med*. May 1986; 314:21: 1380-86.
- Delbanco TL, Meyers KC, Segal AB and EA. Paying the Physicians Fee-Blue Shield and the Reasonable Charge. *N Engl J Med*. 1979; 301:1314-20.
- DeWalt T. Wrongful life and Wrongful birth: The current status of negligent genetic counseling. *Cooley Law Review*. January 1985; 3:1:175-191.
- Dolenc DA, Dougherty CJ. DRGs: The Counterrevolution in Financing Health Care. *Hastings Center Report*. 1985; 19-29.
- Dwyer JM. Scientific Criteria for Adopting Health Screening Measures. *Ped Nurs*. 1983; 9:195-7.
- Feeny D, Tomkins DJ. Letter to the Editor: The Usefulness of Chromosome Banding in Pre and Postnatal Service Cytogenetics: A Reconsideration. *Am J Med Gen*. 1981; 9:79-87.
- Fisher NL, Starr ED, Greene T, Hoehn H. Utility and Limitations of Chromosome Banding in Pre and Postnatal Service Cytogenetics. *Am J Med Gen*. 1980; 5:285-94.
- Gabel J, Ermann D, Rice T, et al. The Emergence and Future of PPOs. *Hosp Management Rev*. 1986; 5:4.
- Geisel J. Insurers Protest State-mandated Health Benefits. *Business Insurance*. March 4, 1985; P3,43.
- Gin H, Larregain F. Legislation du Diabete (2e partie). *La Presse Medicale*. 1985; 14:1684-5.
- Gonnella JS, Hornbrook MC, Louis DZ. Staging of Disease - A Case—Mix Measurement. *JAMA*. 1984; 251:637-46.
- Greenstein RM. Clinical Genetics Programs and Service Reimbursement. *New England Regional Genetics Group Meeting Presentation*. 1981; pl-6.
- Greenstein RM. Third Party Reimbursement. 1-4.
- Hamme JM, Tillman E. DRGs and Long Term Care: Part One. *Contemp Adm Long Term Care*. 1984; 7:25-6.
- Harrison MR. The Anencephalic Newborn as Organ Donor. *Hastings Center Report*. 1986; 16:21-3.
- Health Cost Management Resource Center. CT Business Coalition on Health. Flexible Spending Accounts. Internal Revenue Code Section 125. Proposed Regulations. May 1984; P1-24.
- Held PJ, Holahan J. Containing Medicaid Costs in a year of Growing Physician supply. *Health Care Financing Reviews*. 1985; 7:1:40
- Hirsh HL. The Legal Noose Gets Tighter. *Legal Medicine*. 1982; 187-211.



- Hospital Management Review. HMO Dissatisfaction Increasing, Says HMO/PPO Expert; Are 'Preferred Supplier' Networks Next? Hosp Management Rev. 1986; 5:4-5.
- Huether CA. Projection of Down's Syndrome Births in the United States 1979-2000, And the Potential Effects of Prenatal Diagnosis. AJPH. 1983; 73:1186-9.
- Iglehart JK. Canada's Health Care System. N Engl J Med. July 1986; 315:3:202-8.
- Iglehart JK. Canada's Health Care System. N Engl J Med. Sept. 1986; 315:12:778-84.
- International Medical News Service. States Increasing Care for Medically Indigent. Pediatric News. March 1985; 68.
- Jencks SF, Dobson A. Evaluation Options for Reforming Medicare's Physician Payment Process—Physician DRGs and Alternatives. (Draft Report). Health Care Financing Administration, Office of Research. 1984.
- Jencks S, Dobson A. Strategies for Reforming Medicare's Physician Payments. Physician Diagnosis-Related Groups and Other Approaches. N Engl J Med. June 6, 1985; 312:23:1492-1499.
- Johnson DE. Life, Death and the Dollar Sign—Medical Ethics and Cost Containment. JAMA. 1984; 252:223-4.
- Kastiel DL. Insurers, Consultants Oppose Bill Forcing Well-Child Coverage. Business Insurance. April 1, 1985, 3,12.
- Kennelly BB. A Family Guide to Medicare. Congresswoman Reports. Fall 1985.
- Kolata G. Genetic Screening Raises Questions for Employers and Insurers. Science. 1986; 232:317-19.
- Lane LF. Understanding Long Term Care Policy and the Consequences of Reimbursement. Pride Inst J Long Term Health Care. 1983; 2:7-20.
- LeBrun P. Payers Step Up Roles in Discharge Planning. Hospitals. 1985; 98-102.
- Leroux EA. One Way to Hold Down Medical Costs. Hartford Courant. Nov. 11, 1985.
- Letter to the Editor., Olson-Garewal JK. Cost Containment and the CPC. N Engl J Med. 1986; 315:1297.
- Letter to the Editor., Resnick GD. Testing in Prepaid Versus Fee-For-Service Group Practices. N Engl J Med. 1986; 315:1295.
- Lurie N, Ward NB, Sharpiro MF, et al. Termination of Medi-Cal benefits—A Follow-up Study One Year Later. N Engl J Med. 1986; 314:1266-68.
- Malpractice Update: Lack of Genetic Counseling Violated Standard of Practice. Contemporary OB-GYN. July 1986; 61.
- Ma P, Piazza F. Cost of Treating Birth Defects in State Crippled Children's Services, 1975. Public Health Reports. 1979; 94:420-4.
- Marmor TR, Klein R. Cost vs. Care: America's Health Care Dilemma Wrongly Considered. Hosp Management Rev. 1986; 5:11.
- McNamara DG, Latson LA. Long-Term Follow-Up of Patients With Malformations for Which Definitive Surgical Repair Has Been Available for 25 Years or More. Am J Cardiol. 1982; 50:560-8.
- Mealey L. Decision Making and Adjustment in Genetic Counseling. Health Soc Work. 1984; 9:124-33.
- Medicare Fee Reforms Considered. Hartford Courant. August 24, 1985; A4.
- Melcher Jr. GW, Berini RY. A Perspective of Insurance Coverage for Genetic Disorders. Washington, D.C.: National Genetics Foundation. 1978.
- Parker JM. Wrongful Life: The Child's Cause of Action for Negligent Genetic Counseling in Texas. St. Mary's Law Journal. Summer 1985; 16:3:639-677.
- Patterson SP. Our Bundle of Responsibility. Am J Obstet and Gyn. 1984; 149:245-50.
- Perloff JK. The UCLA Adult Congenital Heart Disease Program. Am J Cardiol. 1986; 57:1190-2.
- Petitti DB. Competing Technologies; Implications for the Costs and Complexity of Medical Care. N Engl J of Med. Dec. 1986; 315:23:1480-3.
- Reading A. Involvement of Proprietary Chains in Academic Health Centers. N Engl J Med. 1985; 313:194-97.
- Reiss JB. Primer: The Purchase and Sale of Health Care under a Prospective Payment System. Personal Communication. Dechert Price & Rhoads, Philadelphia. 1983; p1-33. Roberts CJ, Farrow SC, Charny MC. How Much Can the NHS Afford to Spend to Save a Life or Avoid a Severe Disability? Lancet. 1985; 1:89-91.
- Robinson A. Genetic Screening; Medical Progress Prompts Ethical Questions. AORN Journal. 1986; 43:1137-42.
- Rollnick BR. A Time Analysis of a Genetic Counseling Delivery System. Birth Defects. 1984; 20:208-12.
- Romeo A, Wagner J, Lee R. Prospective Reimbursement and the Diffusion of New Technologies in Hospitals. Journal of Health Economics 3. 1984; 1-24.
- Rowley PT, Loader S, Walden ME. Toward Providing Parents the Option of Avoiding the Birth of the First Child with Cooley's Anemia: Response to Hemoglobinopathy. Ann NY Acad Sci. 1985; 445:408-16.
- Rubin RJ. Financing Long-Term Care. N Engl J Med. 1982; 306:1494.
- Sadovnick AD, Baird PA. Reproductive Counselling for Multiple Sclerosis Patients. Am J Med Genet. 1985; 20:349-54.

- Sadovnick AD, Baird PA. Maternal Age-Specific Costs of Detecting Down Syndrome and Neural Tube Defects. *Canadian J Pub Health*. 1982; 73:248-50.
- Schur C, Sall L. Annotated Bibliography of the National Health Care Expenditures Study. U.S. Department of Health and Human Services. 1-70.
- Schwartz HA. Billing Medicare, Medicaid. *Massachusetts Med*. July/August 1986; 15-17.
- Scriber CR, Bardenis M, Cartier L, et al. Beta-Thalassemia Disease Prevention: Genetic Medicine Applied. *Am J Hum Gen*. 1984; 36:1024-38.
- Sinnock P, Bauer DW. Reimbursement Issues in Diabetes. *Diabetes Care*. 1984; 7:291-6.
- Smits H. The Clinical Context of Technology Assessment. *Journal of Health Politics, Policy & Law*. Spring 1984; 9:1:31-40.
- Smits H. The PSRO in Perspective. *N Engl J Med*. July 30, 1981; 305:253-59.
- Smits H, Feder J, Scanlon W. Medicare's Nursing-Home Benefit: Variations in Interpretation. *N Engl J Med*. Sept 30, 1982; 307:855-62.
- Sonnenburg MA. A Preference for Nonexistence: Wrongful Life and a Proposed Tort of Genetic Malpractice. *Southern California Law Review*. January 1982; 55:2:477-510.
- Stevens C. What's Happened to Those Big Prepaid-Care Savings? *Hosp Management Rev*. 1986; 5:9.
- Taylor H, Kagay M. The HMO Report Card: A Closer Look. *Hosp Management Rev*. 1986; 5:8.
- Thom H, Campbell AGM, Farr V, et al. The Impact of Maternal Serum Alpha Fetoprotein Screening on Open Neural Tube Defect Births in North-East Scotland. *Prenatal Diag*. 1985; 5:15-19.
- Ullmann SG. The Impact of Quality on Cost in the Provision of Long-Term Care. *Inquiry*. 1985; 22:293-302.
- Valdez RB, Leibowitz A, Ware JE, et al. Health Insurance, Medical Care, and Children's Health. *Pediatrics*. 1986; 77:124-28.
- Vladeck BC. Diagnosis Related Group-Based Hospital Payment: The Real Issues. *Bull NY Acad Med*. 1986; 62:46-54.
- Waitzkin H, Akin BV, de la Maza LM, et al. Deciding Against Corporate Management of a State-Supported Academic Medical Center. *N Engl J Med*. 1986; 315:1299-1304.
- Wald N, Oppenheimer. Letter to the Editor. How Much Can the NHS Afford to Spend to Save a Life or Avoid a Severe Disability? *Lancet*. 1985; 1:p80.
- Wallack S. Where Are New Resources for Financing Long Term Care? *Pride Inst J Long Term Health Care*. 1983; 2:21-40.
- Walters L. The Ethics of Human Gene Therapy. *Nature*. 1986; 320:225-7.
- Weitzel H. Alpha-Fetoproteins in Obstetrics. *Gynakologe*. 1983; 16:148-54.
- Wertelecki V. Minimal Southeastern Regional Database Proposed Conceptual Items. Personal Communication. 1984; 1-3.
- Williams L. HCFA Examines 'RUGs' for Long Term Care Reimbursement Plan. *Today's Nurs Home*. 1983; :1,7.
- Williamson RA, Hanson JW, Grant SS. Maternal Serum Alpha-fetoprotein Screening: Report of a Pilot Project in Iowa. *Iowa Medicine*. Feb. 1986; 61-4.
- Ziehm DJ. Wrongful Life: An Obstetrical Dilemma. Part II. *Obstet and Gyn*. 1979; 36:596.

## CATEGORY 5—GENERAL DEFINITIONS

### A. Primary References

- Arnett RH. Projections of Health Care Spending to 1990. *Hosp Management Rev.* 1986; 5:10.
- Barganier C, Henson JF, Finley WH. Genetic Counseling in Families at Increased Risk for Neural Tube Defects. *Alabama J Med Sci.* 1985; 22:301-4.
- Beeson D, Douglas R. Prenatal Diagnosis of Fetal Disorders—Part I: Technological Capabilities. *Birth.* 1983; 10:227-32.
- Beeson D, Douglas R, Lunsford TF. Prenatal Diagnosis of Fetal Disorders—Part II: Issues and Implications. *Birth.* 1983; 10:233-42.
- Berk ML, Wilensky GR, Cohen SB. Methodological Issues in Health Surveys: An Evaluation of Procedures Used in the National Medical Care Expenditure Survey. *Evaluation Review.* June 1984; 8:3:307-26.
- Berry HK. The Spectrum of Metabolic Disorders. *Diagnostic Med.* 1984; 39-46.
- Birth Defects Original Article Series. Toward More Effective Genetic Counseling. *Birth Defects Original Article Series.* 1981; 17:136-7.
- Black RB, Furlong R. Impact of Prenatal Diagnosis in Families. *Soc Work Health Care.* 1984;37-50.
- Blendon RJ. Health Policy Choices for the 1990s. *Hosp Management Rev.* 1986; 5:10. Butler BB. Caring for the Family of an Infant with a Genetic Disorder. *Perinatal Press.* 1984; 8:55-7.
- Cohen FL. Genetic Components and Counseling in Renal Disorders. *J Nephrol Nursing.* 1984; 125-9.
- Dansereau L. A Glossary of Common Terms and Abbreviations Used in the DRG System. *DRG Newsletter—St. Francis Hospital and Medical Center, Hartford CT.* Fall 1985.
- Dorner W. Clearing Up the Public's Misconceptions about Health Care. *Ohio State Med J.* July 1985; 81:7:463,65,67.
- Edwoc EE, Seals BF, Kim J-O, et al. Factors Influencing Maternal Estimates of Genetic Risk. *Am J Med Gen.* 1985; 20:491-502.
- Epstein CJ, Childs B, Fraser FC, et al. Genetic Counseling. *Am J Hum Genet.* 19075; 27:240-2.
- Finley WH, Finley SC. The Diagnosis of Genetic Disorders Before Birth. *Southern Med J.* 197669:1486-92.
- Fox JE. Genetic "Engineering"? *Science.* 1985; 230:237-8.
- Gabel J, Ermann D, Rice T, et al. The Emergence and Future of PPOs. *Hosp Management Rev.* 1986; 5:4.
- Gerber P, Pearn JH, Bell J. Prenatal Cytogenetic Diagnosis: Some Potential Legal Implications. *Med J Australia.* 1985; 142:80-3.
- Goldsmith J. 2036: A Health Care Odyssey. *Hosp Management Rev.* 1986; 5:1.
- Harper PS. Chromosomal Abnormalities. *Practical Genetic Counseling.* 1981; University Park Press, Baltimore, Md. 56-65.
- Harper PS, Carfarazi M. Genetic Prediction and Family Structure in Huntington's Chorea. *Brit Med J.* 1965; 290:1929-31.
- Health Resources and Services Administration. Current Publications. U.S. Department of Health and Human Services. Jan. 1986; 1-28.
- Israel BA. Social Networks and Social Support: Implications for Natural Helper and Community Level Interventions. *Health Education Quarterly.* 1985; 12:65-80.
- Kapp MB. Decision-Making in Critical Care: Is the Law an Impediment or a Scapegoat? *Crit Care Med.* 1986; 14:247-50.
- Kenen RH. Genetic Counseling: The Development of a New Interdisciplinary Occupational Field. *Soc Sci Med.* 1984; 18:541-9.
- Lipkin M, Fisher L, Rowley PT, et al. Genetic Counseling of Asymptomatic Carriers in a Primary Care Setting. *Ann Int Med.* 1986; 105:115-23.
- Lorenz RP, Botti JJ, Schmidt CM, et al. Encouraging Patients to Undergo Prenatal Genetic Counseling Before the Day of Amniocentesis. *J Reprod Med.* 1985; 30:933-5.
- Lorenz RP, Willard D, Botti JJ. Role of Prenatal Genetic Counseling Before Amniocentesis—A Survey of Genetics Centers. *J Reproduc Med.* 1986; 31:1-3.
- Mealey L. Decision Making and Adjustment in Genetic Counseling. *Health Soc Work.* 1984; 9:124-33.
- Mennuti MT. Teratology and Genetic Counseling in the Diabetic Pregnancy. *Clin Obstet and Gyn.* 1985; 28:486-95.
- Middleton GF, Lass NJ, Starr P, et al. Survey of Public Awareness and Knowledge of Cleft Palate. *Cleft Palate J.* 1986; 23:58-62.
- Myers TF, Ahmed GS, Anderson CL, et al. A Modification of the International Classification of Diseases for Uniform Coding of Diagnosis, Procedures, and Medications. *Am J Perinatol.* 1985; 2:240-1.
- National Center for Health Services Research and Health Care, Technology Assessment. NCHSR Extramural Research. U.S. Department of Health and Human Services. Oct. 1985; 1-7.
- Oberle I, Camerino G, Heilig R, et al. Genetic Screening for Hemophilia A (Classic Hemophilia) with a Polymorphic DNA Probe. *N Eng J Med.* 1985; 312:682-6.
- Ottensmeyer DJ, Smith HL. Patterns of Medical Practice in an Era of Change. *Hosp Management Rev.* 1986; 5:10.
- Pearce JM. The Use of Ultrasound in the Diagnosis of Congenital Anomalies. *Midwife Health Visitor & Community Nurse.* 1983; 19:82-8.



- President's Commission for the Study of Ethical Problems. Screening and Counseling for Genetic Conditions. Library of Congress. 1983; U.S. Govt Printing Office. 122.
- President's Commission for the Study of Ethical Problems in Medicine, and Biomedical and Behavioral Research. The Evolution and Status of Genetic Services. Genetic Screening and Counseling. 198 ; U.S. Government Printing Office:9-39.
- Reading A. Involvement of Proprietary Chains in Academic Health Centers. N Engl J Med. 1985; 313:194-97.
- Roberts A. Systems of Life No 106—Setting up the Systems-6. Nursing Times. 1983; 49-52.
- Robertson JA. Legal Issues in Fetal Therapy. Sem in Perinatol. d1985; 9:136-42.
- Schur C, Sall L. Annotated Bibliography of the National Health Care Expenditures Study. U.S. Department of Health and Human Services. 1-70.
- Scriver CR, Laberge C, Clow CL, et al. Genetics and Medicine: An Evolving Relationship. Science. 1978; 200:946-52.
- Shear CS, Wellman NS, Nyhan WL. Phenylketonuria: Experience with Diagnosis and Management. Heritable Disorders of Amnio Acid Metabolism. 1974; John Wiley Sons, Inc.:141-59.
- Sissine FJ, Stelle MW, Garver KL, et al. Statistical Analysis of Genetic Counseling Impacts—A Multi-Method Approach to Retrospective Date. Evaluation Rev. 1981; 5:745-57.
- Sorenson JR. Clinics, Counselors, and Clients. Birth Defects Original Article Series. 1981; 17;4:31-50.
- Stoll C, Roth M-P, Dott B, et al. Usefulness of a Registry of Congenital Malformations for Genetic Counseling and Prenatal Diagnosis. Clin Genet. 1986; 29:204-10.
- Thurmon TF. Practical Concepts About Risks and Risk Management. Consultant. 1985; 43-56.
- Turnbull AC. Fetal Preventive Medicine. Birth Defects: Original Article Series. 1985; 21:37-54.
- Vanselow NA. Academic Health Centers: Can They Survive? Hosp Management Rev. 1986; 5:4.
- Vladeck BC. Health, Healthcare Executives, and Their Communities. Hosp Management Rev. 1986; 5:1.
- Vladeck BC. Diagnosis Related Group-Based Hospital Payment: The Real Issues. Bull NY Acad Med. 1986; 62:46-54.
- Warsof SL, Rodeck CH. Fetoscopy. Midwives Chronicle & Nursing Notes. 1983; 194-5.
- White I, Magnay DE. Screening for Down's Syndrome. Brit Med J. 1985; 291:1725.
- Williams JB, Feldman ML. Life After Merger: The Human Resource Factor. Hosp Management Rev. 1986; 5:7.
- World Health Organization. Report of WHO Advisory Group on Hereditary Diseases. World Health Organization. 1982; HMG/AG/82.4:pp17.
- Young I, Nugent Z, Grimm T. Autosomal Recessive or Sex Linked Recessive: A Counselling Dilemma. J Med Gen. 1986; 23:32-4.
- Young RS, Jorgenson RJ, Shapiro SD. Efficiency of and Patient Preference for Three Counseling Formats. J Craniofacial Genet & Devel Bio. 1986; 6:3-14.

## B. Secondary References—General Definitions

- Abuelo DN, Posenstein J, Sheff M. Tay-Sachs Disease: Knowledge and Attitudes of the Rabbinical Community. *RI Med J.* 1985; 68:225-6.
- Adler J. Birth Defects, Every Parent's Nightmare. *Newsweek.* March 16, 1987; 57-66.
- Anionwu EN. Sickle Cell Disease: Screening and Counselling in the Antenatal and Neonatal Period—Part 1. *Midwife Health Visitor & Community Nurse.* 1983; 19:402-6.
- Anionwu EN. Sickle Cell Disease: Screening and Counselling in the Antenatal and Neonatal Period—Part 2. *Midwife Health Visitor & Community Nurse.* 1983; 19:440-3.
- Annas GJ, Elias S. Maternal Serum AFP: Educating Physicians and the Public. *AJPH.* 1985; 75:1374-5.
- Bapat VV. Connecticut Genetic Diseases Program. Connecticut Dept. of Health, Maternal & Child Health Div. 1984; 1-10.
- Battistella RM, Weil TP. Procompetitive Health Policy: Benefits and Perils. *Hosp Management Rev.* 1986; 5:11.
- Beeson D, Golbus MS. Decision Making: Whether or Not to Have Prenatal Diagnosis and Abortion for X-Linked Conditions. *Am J Med Gen.* 1985; 20:107-14.
- Bender AN. Diagnosis: Muscular Dystrophy. *Hospital Medicine.* 1984; 95-125.
- Bloom AD. Prenatal Diagnosis—Available Alternatives. *Hospital Practice.* 1983; 227-46.
- Bewman JE. Is A National Program to Prevent Sickle Cell Disease Possible? *Am J Ped Hematol Oncol.* 1983; 5:367-72.
- Bush JW, Chen MM, Patrick DL. Health Status Index in Cost Effectiveness: Analysis of PKU Program. *Health Status Indexes.* 1973; Hospital Research and Educational Trust, Chicago. 173-208.
- Cassak D. Extended Product Line—Preparing for the Consumer Revolution in Health Care. *Hosp Management Rev.* 1986; 5:1.
- Childs B. Genetic Decision Making and Pastoral Care—The Dimensions of the Problem. *Hospital Practice.* 1983; 96D-96X.
- Clare MD. Home Care of Infants and Children with Cardiac Disease. *Heart & Lung.* 1985; 14:218-22.
- Clochesy JM, Whittaker AA, Murdaugh CL. Hypoplastic Left Heart Syndrome: A Review and the Report of Two Cases. *Heart & Lung.* 1986; 15:23-8.
- Collins DL. Perspectives in Genetic Counseling. National Society of Genetic Counselors, Inc. June 1986; 8;2:1-5.
- Davis DH, Hawkins JW. High-Risk Maternal and Neonatal Transport: Psychosocial Implications for Practice. *Dimensions of Critical Care Nursing.* 1985; 4:368-79.
- Davis C. Interview—Hospitals and PPS: Exemplary Beginnings. *Hospitals.* 1985; 96-7.
- de Lissovoy G, Rice T, Ermann D, et al. Preferred Provider Organizations: Today's Models and Tomorrow's Prospects. *Inquiry.* Spring 1986; 23:7-15.
- Doubilet P, Wainstein MC, McNeil BJ. Use and Misuse of the Term "Cost Effective" in Medicine. *N Engl J Med.* 1986; 314:253-55.
- Ermann D. Health Maintenance organizations: the future of the for-profit plan. *JACM.* 1986; 9;2:72-84.
- Fletcher JC. Ethical Considerations in and Beyond Experimental Fetal Therapy. *Sem Perinatol.* 1985; 9:130-5.
- Ford LC. The Future of Pediatric Nurse Practitioners. *Pediatrics.* 1979; 64:113-14.
- Fuhrmann W, Weitzel HK. Maternal Serum Alpha-fetoprotein Screening for Neural Tube Defects. *Hum Gen.* 1985; 69:47-61.
- Greenstein RM. Connecticut Reimbursement Policy. Personal Communication, RM Greenstein. 1982; 2.
- Grossman LK, Holzman NA, Charney E, et al. Neonatal Screening and Genetic Counseling for Sickle Cell Trait. *AJDC.* 1985; 139:124-244.
- Horwell DH, Loeffler FE. A New Approach to Antenatal Diagnosis. *Midwife Health Visitor & Community Nurse.* 1983; 19:396-8.
- Iowa State Department of Public Health. Update on Newborn Screening. *Iowa Medicine.* 1986; 139-40.
- Jackson LG. First-Trimester Diagnosis of Fetal Genetic Disorders. *Hospital Practice.* 1985; 39-48.
- Jeddeloh NP, Bierig JR, Allen HS. Implementing DRGs: Developing Effective Strategies (Based on the Final 1984 Regulations). Center for Educational Development. 1984; (Videotape).
- Jolley J. Antenatal Screening for Fetal Abnormalities: Experiences in a District General Hospital. *Radiography.* 1983; 49:157-9.
- Kelly TE. Essentials of Genetic Counseling (Part 1). *Hospital Medicine.* 1985; 110-32.
- Kelly TE. Essentials of Genetic Counseling (Part 2). *Hospital Medicine.* 1985; 94-116.
- Kelly TE. Approaches to Clinical Diagnosis. *Clinical Genetics and Genetic Counseling.* 1980; Yearbook Medical Publishers, Inc., Chicago. 183-261.
- Knapp RE. The development of Outpatient DRGs. *J Ambulatory Care Management.* May 1983; 1-11.
- Korner H, Rodriguez L, Yero JLF. Maternal Serum Alpha-fetoprotein Screening for Neural Tube Defects and Other Disorders Using an Ultramicro-ELISA. *Hum Genet.* 1986; 73:60-3.
- Kunz (Ed). *AMA Family Medical Guide.* Random House Publications. 1982; 739-53.
- Laberge C, Scriver CR, Clow CL, et al. Le Réseau de médecine Génétique du Québec: Un Programme Intégré de Diagnostic, Conseil. *L'Union Médicale du Canada.* 1975; 104:428-57.

- Lappe M. The New Technologies of Genetic Screening—The Predictive Power of the New Genetics. The Hastings Center Report. 1984; 18-21.
- Leslie LA, Swider SM. Changing Factors and Changing Needs in Women's Health Care. Nurs Clin N Am. 1986; 21:111-23.
- Levinson NG, Warburton SW, Veatch RM, et al. The Ethics of Capitation. Massachusetts Medicine. July/August 1986; 37-48.
- Main DM, Mennuti MT. Neural Tube Defects: Issues in Prenatal Diagnosis and Counseling. Obstet Gynecol. 1986; 67:1-16.
- Mayer TR, Mayer GG. HMOs: Origins and Development. N Engl J Med. 1985; 312:590-4.
- McDevitt R, Buczek W. Medicaid program characteristics: Effects on health care expenditures and utilization. Health Care Financing Review. Winter 1985; 7:2:1-29.
- Mearig JS. Facial Surgery and an Active Modification Approach for Children with Down Syndrome: Some Psychological and Ethical Issues. Rehab Lit. 1985; 46:72-7.
- Merz B. Geneticists Ponder Ethical Implications of Screening. JAMA. 1985; 254:3160.
- Meyers TL, Prouty LA. Survey of Costs of Genetics Services. Johnson City, TN: Department of Pediatrics, East Tennessee State University. 1984.
- Michael CA. Routine Antenatal Screening. Australian Family Physician. 1985; 14:1195-9.
- Murray TH. The Final, Anticlimactic Rule on Baby Doe. Hastings Center Report. 1985; 5-9.
- Murray TH. The New Technologies of Genetic Screening—The Social Context of Workplace Screening. The Hastings Center Report. 1984; 21-3.
- Norgaard-Pedersen B, Bagger P, Bang J, et al. Maternal-Serum-Alpha-fetoprotein Screening for Fetal malformations in 28,062 Pregnancies. Acta Obstet Gynecol Scand. 1985; 64:511-14.
- Parver AK. Third-Party Payment for Nutrition Care Services. JAMA. 1984; 84:693-700.
- Person P-H, Kullander S. Long-term Experience of General Ultrasound in Pregnancy. Am J Obstet Gynecol. 1983; 146:942-47.
- Reif M, Baitsch H. Psychological Issues in Genetic Counseling. Hum Genet. 1985; 70:193-9.
- Rice N, Doherty R. Reflections on Prenatal Diagnosis: The Consumer's Views. Soc Work Health Care. 1982; 8:47-57.
- Schieber GJ, Burney IL, Golden JB, Knaus WA. Physician Fee Patterns Under Medicare: A Descriptive Analysis. N Engl J Med. 1976; 294:1089-1093.
- Schimke RN. Genetic Counseling—The Physician's Experience. Hops Pract. 1983; 18:35-40.
- Sitzer KH, Gardner LI. Genetic Counseling—Letter to the Editor. JAMA. 1985; 253:202-3.
- Tanner DJ. Health Care Cost-Containment in a Changing Health Care World. Drug Intell Clin Pharm. 1985; 19:291-2.
- U.S. Department of Health E.A.W. The Development of Legislation and Regulation for PKU Screening. Genetic Screening for Inborn Errors of Metabolism. DHEW Publication No. (MSA)77-5124. 44-87.
- U.S. Dept. of HEW. Third Party Reimbursement-Basic Concepts Title XX—Social Services Funding. Natl. Clearinghouse for Drug Abuse Information Report Series 35 Issue A. Wash. D.C. Gov. Printing Offices. 1975.
- Vitello SJ. The Tatro Case: Who Gets What and Why. Exceptional Children. 1986; 52:353-6.
- Walters I, Baysinger M, Buchanan I, et al. Complications of Sickle Cell Disease. Nursing Clin of N America. 1983; 18:139-84.
- Working Committee on Definition of Genetic Counseling. Definition of Genetic Counseling and the Role of the Genetic Counselor Trained at the Master's Level. National Meeting on Genetic Counseling, Williamsburg, VA. 1979; 1-2.

## CATEGORY 6—ETHICS

### A. Primary References

- Anderson WF. Human Gene Therapy: Scientific and Ethical Considerations. *J Med & Philos.* 1985; 10:275-91.
- Baelz P, Barron SL, Burrow J, et al. The Prognosis for Babies with Meningomyelocele and High Lumbar Paraplegia at Birth. *Lancet.* 1985; 996-7.
- Bartholome WG. Imperiled Newborns Raise Moral Doubts. *Hastings Center Report.* 198; 46-7.
- Baskin J. Prenatal Testing for Tay-Sachs Disease in the Light of Jewish Views Regarding Abortion. *Issues in Health Care of Women.* 1983; 4;1:41-56.
- Baumiller RC. Clergy Involvement—A Dimension of Real Need. *Hospital Practice.* 1983; 38A-38P.
- Belton B. Wrongful Life: A Legislative Solution to Negligent Genetic Counseling. *University of San Francisco Law Review.* 1983; 18:11-108.
- Berg K, Fletcher J. Ethical and Legal Aspects of Predictive Testing. *Lancet.* 1986; 1:1043.
- Bergner L. Amniocentesis for Sex Identification—Letter to the Editor. *N Engl J Med.* 1980; 302:525.
- Bernstein A. What Compensation for an Unwanted Life? *Hospitals.* Dec. 1984; 58:90.
- Bloom AD. Prenatal Diagnosis—Available Alternatives. *Hospital Practice.* 1983; 227-46.
- Bosk C. The Fieldworker as Watcher and Witness. *Hastings Center Report.* 1985; 10-14.
- Bowman JE. Is A National Program to Prevent Sickle Cell Disease Possible? *Am J Ped Hematol Oncol.* 1983; 5:367-72.
- Brower C. Wrongful Birth: Judicial Reticence with an Emerging Tort: The Negligent Performance of Genetic Counseling. *University of Dayton Law Review.* 1981; 6:115-33.
- Butler WJ. Ethics and Patients' Rights. *Consultant.* 1986; 87-92.
- Candee D, Puka B. An Analytic Approach to Resolving Problems in Medical Ethics. *J Med Ethics.* 1984; 2:61-70.
- Canter EF. Employment Discrimination Implications of Genetic Screening in the Workplace under Title VII and the Rehabilitation Act. *Am J Law and Med.* 1984; 10:323-47.
- Childs B. Genetic Decision Making and Pastoral Care—The Dimensions of the Problem. *Hospital Practice.* 1983; 96D-96X.
- Clayden C, Mattar N. Ethics and the Severely Malformed Infant: Report on a Multi-disciplinary Workshop. *J Med Ethics.* 1984; 2:71-2.
- Coplan J. Wrongful Life and Wrongful Birth: New Concepts for the Pediatrician. *Pediatrics.* 1985; 75:65-72.
- Crawshaw R, Garland MJ, Hines B, et al. Oregon Health Decisions—An Experiment With Informed Community Consent. *JAMA.* 1985; 254:3213-6.
- Cray E. The "Wrongful Life" Dilemma. *California Lawyer.* September 1982; 52;6:53-55;58-59;96-98.
- Deitch R. Research on Embryos. *Lancet.* 1985; 469.
- DeWalt T. Wrongful life and wrongful birth: The current status of negligent genetic counseling. *Cooley Law Review.* January 1985; 3;1:175-191.
- Downie RS. Ethics and Surveys. *J Med Ethics.* 1984; 2:77-8.
- Dresser RS, Boisaubin EV. Ethics, Law, and Nutritional Support. *Arch Intern Med.* 1985; 145:122-4.
- Elkins TE, Crutcher D, Spinnato J, et al. Baby Doe: Is There Really a Problem? *Obstet Gynecol.* 1985; 65:492-5.
- Ershkowitz M. Human Service Delivery Policy-Making in American Cities: The Case of Genetic Disease Trait-Testing Programs. *J Health Hum Res Admin.* 1980; 3:204-28.
- Field RI. Biological Monitoring and Genetic Screening in the Industrial Workplace: A Synopsis and Analysis. *Law, Medicine & Health Care.* 1983; 125-9.
- Fletcher JC. Ethical Issues in and Beyond Prospective Clinical Trials of Human Gene Therapy. *J Med & Philos.* 1985; 10:293-309.
- Fletcher JC. Ethical Considerations in and Beyond Experimental Fetal Therapy. *Sem Perinatol.* 1985; 9:130-5.
- Fletcher JC, Berg K, Tranoy KE. Ethical Aspects of Medical Genetics. *Clin Gen.* 1985; 27:199-205.
- Furow BR. Impaired Children and Tort Remedies: The Emergence of a Consensus. *Law, Medicine & Health Care.* 1983; 148-54.
- Gillon R. Conclusion: The Arthur Case Revisited. *Brit Med J.* 1986; 292:543-5.
- Gostin L. A Moment in Human Development: Legal Protection, Ethical Standards and Social Policy on the Selective Non-Treatment of Handicapped Neonates. *Am J Law & Med.* 1985; 11:31-78.
- Harrison MR. The Anencephalic Newborn as Organ Donor. *Hastings Center Report.* 1986; 16:21-3.
- Harris RL. Information, Risk and Professional Ethics. *Am Ind Hyg Assoc J.* 1986; 47:67-71.
- Health Law Digest. Woman Whose Fetus Died Because of Allowed Negligent Amniocentesis Procedure May Not Recover Damages for Emotional Distress. *Health Law Digest.* 1985; 13:22-3.
- Hill IR. Liability and In-Vitro Fertilization. *Med Sci Law.* 1985; 25:270-4.

- Hines B. Health Policy on the Town Meeting Agenda. *Hastings Center Report*. 1986; 5-7.
- Hines BL. Oregon And American Health Decisions. U.S. Department of Health and Human Services. July 1985; 1-45.
- Hirsh HL. The Legal Noose Gets Tighter. *Legal Medicine*. 1982; 187-211.
- Ignatieff M. The Needs of Strangers. An Essay on Privacy, Solidarity, and the Politics of Being Human. Viking Penguin Inc. 40 W. 23rd St. NY, NY. 1985; 1- .
- Johnson DE. Life, Death and the Dollar Sign—Medical Ethics and Cost Containment. *JAMA*. 1984; 252:223-4.
- Kliegman RM, Mahowald MB, Youngner SJ. In Our Best Interests: Experience and Workings of an Ethics Review Committee. *J Pediatrics*. 1986; 108:178-88.
- Knoll E, Lundberg GD. Informed Consent and Baby Fae. *JAMA*. 1985; 254:3359-60.
- Kobrin J. Confidentiality of Genetic Information. *UCLA Law Review*. 1983; 20:1283-1315.
- Kolata G. Genetic Screening Raises Questions for Employers and Insurers. *Science*. 1986; 232:317-19.
- Kopelman LC. Protesting the Proposed Federal Regulations for Critically Sick Infants. *NCMJ*. 1985; 46:265-9.
- Kuhse H, Singer P. Handicapped Babies: A Right to Life? *Nursing Mirror*. 1985; 160:17-20.
- Landsman RM. Letter to the Editor—Ethics, Law, and Nutritional Support. *Arch Intern Med*. 1985; 145:2130-1.
- Lang GC. 'Baby Doe'—A Medical Ethical Issue. *West J Med*. 1985; 142:837-41.
- Lenke RR, Nemes JM. Wrongful Birth, Wrongful Life: The Doctor Between a Rock and a Hard Place. *Obstet & Gynec*. 1985; 66:719-722.
- Levine C. The Case of Baby Jane Doe. *The Hastings Center Report*. 1984; 10-19.
- Levinsky NG, Warburton SW, Veatch RM, et al. The Ethics of Capitation. *Massachusetts Medicine*. July/August 1986; 37-48.
- Main DM, Mennuti MT. Neural Tube Defects: Issues in Prenatal Diagnosis and Counselling. *Obstet Gynecol*. 1986; 67:1-16.
- Malpractice Update: Lack of Genetic Counseling Violated Standard of Practice. *Contemporary OB-GYN*. July 1986; 161.
- Martin D. Withholding Treatment from Severely Handicapped Newborns: Ethical-legal Issues. *Nursing Administration Quarterly*. 1985; 9:47-56.
- Mearig JS. Facial Surgery and an Active Modification Approach for Children with Down Syndrome: Some Psychological and Ethical Issues. *Rehab Lit*. 1985; 46:72-7.
- Merowitz M. Some Ethical Dilemmas in Empathic Provision of Long-term Clinical Care. *J. Geriatr. Psychiatry*. 1985; 18:175-9.
- Merz B. Geneticists Ponder Ethical Implications of Screening. *JAMA*. 1985; 254:3160.
- Moskop JC, Saldanha RL. The Baby Doe Rule: Still a Threat. *Hastings Center Report*. 1986; 16:8-14.
- Murray TH. The Final, Anticlimactic Rule on Baby Doe. *Hastings Center Report*. 1985; 5-9.
- Nolan-Haley JM. Amniocentesis and the Apotheosis of Human Quality Control. *J of Legal Med*. 1981; 2:3347-363.
- Parker JM. Wrongful Life: The Child's Cause of Action for Negligent Genetic Counseling in Texas. *St. Mary's Law Journal*. Summer 1985; 16:3:639-677.
- Pedulla DM, Puissegur-Lupo ML. Moral Dilemma: Two Views. *Postgrad Med*. 1986; 79:34-5.
- Peters JD, Fineberg KS. Genetic Counseling and Screening: Standards of Care, Customary Practice, and Legal Liability. *Trial*. January 1984; 1:82-89.
- Pierson M. Les Aspects De L'Ethique Medicale Dans Le Conseil Genetique. *J Genet Hum*. 1984; 32:251-55.
- Pinch WJ. Allocation of Scarce Resources: Critical Care Nursing Dilemma. *Dimensions of Critical Care Nursing*. 1985; 4:164-73.
- Reif M, Baitsch H. Psychological Issues in Genetic Counselling. *Hum Genet*. 1985; 70:193-9.
- Rhoden NK, Arras JD. Withholding Treatment from Baby Doe: From Discrimination to Child Abuse. *Milbank Memorial Fund Quarterly/Health and Society*. 1985; 63:18-51.
- Robbins A, Freeman PK. Congress Looks at the Evidence. *J Public Health Policy*. 1985; 335-9.
- Robinson A. Genetic Screening; Medical Progress Prompts Ethical Questions. *AORN Journal*. 1986; 43:1137-42.
- Schimke RN. Genetic Counseling—The Physician's Experience. *Hops Pract*. 1983; 18:35-40.
- Schulman RM. Genetic Screening and the Law. *Medical Trial Technique Quarterly*. 295-303.
- Seals BF, Edwo EE, Williamson RA, et al. Moral and Religious Influences on the Amniocentesis Decision. *Soc Biol*. 32:13-30.
- Sitzer KH, Gardner LI. Genetic Counseling—Letter to the Editor. *JAMA*. 1985; 253:202-3.
- Smith GP. Defective Newborns and Government Intermeddling. *Med Sci Law*. 1985; 25:44-8.
- Sonnenburg MA. A Preference for Nonexistence: Wrongful Life and a Proposed Tort of Genetic Malpractice. *Southern California Law Review*. January 1982; 55:2:477-510.
- Steinbock B. The Logical Case for "Wrongful Life". *Hastings Center Report*. 1986; 15-20.



- Suslak L, Price DM, Desposito F. Transmitting Balanced Translocation Carrier Information Within Families. A Follow-Up Study. *Am J Med Gen.* 1985; 20:227-32.
- Tammelleo AD. If You Want To Stop Treating a Patient. *RN.* 1986; 59-60.
- Taub S. The Current Status of Actions for Wrongful Life and Wrongful Birth. *Leg. Med.* 1985; 180-95.
- Taub S. Wrongful Life—Its Problems Are Not Just Semantic: A Reply to Furrow. *Law, Medicine & Health Care.* 1982; 208-15.
- Temple MJ. Preamniocentesis Counseling. *Hospital Practice.* 1983; 94E-94T.
- Uzych L. Ethical Aspects of Predictive Testing. *Lancet.* 1986; 1445-6.
- Waddill GC. Genetic Screening: A Medicolegal Time Bomb? *Med Lab Observer.* 1983; 55-8.
- Walters L. The Ethics of Human Gene Therapy. *Nature.* 1986; 320:225-7.
- Weil WB. The Baby Doe Regulations: Another View of Change. *Hastings Center Rep.ort.* 1986; 12-13.
- Woolfe T. Medicine's Goal Overshadowed by Technology. *Hartford Courant.* November 17, 1985; B1-B3.
- Young ID. Ethical Dilemmas in Clinical Genetics. *J Med Ethics.* 1984; 2:73-6.
- Ziehm DJ. Wrongful Life: An Obstetrical Dilemma. Part II. *Obstet and Gyn.* 1979; 36:596.

## B. Secondary References--Ethics

- Anderson WF. Human Gene Therapy: Scientific and Ethical Considerations. *Recombinant DNA Tech Bull.* 1985; 8:55-63.
- Andrews LB. State Laws and Regulations Governing Newborn Screening. American Bar Foundation, Chicago. 1985; 167.
- Bernard J. Economic and Moral Consequences of Medical Progress. *Revue Medical Suisse Rommande.* 1982; 102:83-93.
- Blank RH. Public Policy Implications of Human Genetic Technology: Genetic Screening. *J Med Phil.* 1982; 7:355-74.
- Buchanan RJ, Minor JD. Legal Aspects of Health Care Reimbursement. *J Legal Med.* 1985; 6:553-62.
- Caper P, Blumenthal D. What Price Cost Control? *N Engl J Med.* 1983; 308:242-44.
- Carter PE, Pearn JH, Bell J, Marin N, Anderson AG. Survival in trisomy 18. Life tables for use in genetic counselling and clinical pediatrics. *Clinical Genetics.* 1985; 27:59-61.
- Chapman S. What Are Your Odds in the Prenatal Gamble? *Leg Aspects of Med Prac.* Mar 1979; 30-6.
- Clayton BE. Problems Affecting the Community—Population Screening. *J Clin Path.* 8:145-9.
- Czeizel A, Metneki J. Recurrence Risk After Neural Tube Defects in a Genetic Counseling Clinic. *J Med Gen.* 1984; 21:413-16.
- Davies BL. Decision Making in Prenatal Genetic Diagnosis. *Issues in Health Care of Women.* 1983; 4:69-76.
- Edwards RG, Purdy JM, Walters WAW, et al. Human Conception in Vitro: Proceedings of the First Bourn Hall Meeting. *J. of Medical Ethics.* June 1984; 16:2:99.
- England WL, Roberts SD. Immunization to Prevent Insulin-Dependent Diabetes Mellitus? The Economics of Genetic Screening and Vaccination for Diabetes. *Annals of Internal Med.* 1981; 14:395-400.
- Fox JE. Genetic "Engineering"? *Science.* 1985; 230:237-8.
- Fuchs VR. The 'Rationing' of Medical Care. *New Engl J of Med.* Dec. 13, 1984; 311:24:1572-3.
- Grossman LK, Holtzman NA, Charney E, Schwartz AD. Neonatal Screening and Genetic Counseling for Sickle Cell Trait. *Am J Disease Children.* March 1985; 139:241-244.
- Hook EB. Invited Editorial: Genetic Triage and Genetic Counseling. *Am J Med Gen.* 1984; 17:535-538.
- Hubbard R, Henifin MS. Genetic Screening of Prospective Parents and of Workers: Some Scientific and Social Issues. *Int J Health Services.* 1985; 15:231-51.
- Jansen RPS. Sperm and Ova as Property. *J Med Ethics.* 1985; 11:123-6.
- Kapp MB. Decision-Making in Critical Care: Is the Law an Impediment or a Scapegoat? *Crit Care Med.* 1986; 14:247-50.
- Kaufmann CL, Williams PR. Fetal Surgery: The Social Implications of Medical and Surgical Treatment of the Unborn Child. *Women & Health.* 1985; 10:25-37.
- Letter to the Editor., Klein WJ. Why Saying No to Patients in the United States is So Hard. *N Engl J Med.* 1986; 315:1296-7.
- Neufeld W. Bioengineering: The Promises and the Problems. *Trend Analysis Program, American Council of Life Insurance.* Jan. 1984; P1-27.
- Nitowsky HM. Considerations on Informed Consent. An Office Guide to Prenatal AFP Screening. 1980; AFP Prenatal Screening Project, Foundation for Blood Research, Scarborough, Maine. 15-20.
- President's Commission for the Study of Ethical Problems in Medicine, and Biomedical and Behavioral Research. The Setting of the Report. Screening and Counseling for Genetic Conditions. 1983; U.S. Government Printing Office:15-41.
- Rosenfeld A. At Risk for Huntington's Disease: Who Should Know What and When? *The Hastings Center Report.* 1984; 5-8.
- Scheffler RM, Paringer L. A Review of the Economic Evidence on Prevention. *Med Care.* 1980; 18:473-84.
- Schwartz W, Joskow P. Medical Efficiency Versus Economic Efficiency: A Conflict in Values. *N Engl J Med.* December 28, 1978; 299:6:1462-1464.
- Scott-Samuel A. Screening for Neural Tube Defects. *Lancet.* 1980; 1:550.
- Thurrow LC. Learning to Say 'No'. *New Engl J of Med.* Dec. 13, 1984; 311:24:1569-72.
- Uzych L. Genetic Testing and Exclusionary Practices in the Workplace. *J Public Health Policy.* 1986; 37-57.
- Vurnig P. Long-Gap Esophageal Atresia—Prenatal Diagnosis of Congenital Malformations. *Progress in Pediatric Surgery.* 1986; 19:197-202.
- Walker DB, Feldman A, Vohr BR, Oh W. Cost-Benefit Analysis of Neonatal Intensive Care for Infants Weighing Less Than 1000 Grams at Birth. *Pediatrics.* 1984; 74:20-25.
- Wallace DL. Congress Examines Ethical Issues Given Birth by Genetic Engineering. *Modern Healthcare.* 1984; 114-6.
- Wood C. Get Ready for Bioengineering. *The Bangor (ME) Daily News.* April 7, 1984; 19.

## CATEGORY 7—GENETIC FUNDING

### A. Primary References

- American Society of Human Genetics. Genetic Services Committee. Report on Costs and Payment for Genetic Services. 1985; 1-6.
- Bapat VV. Connecticut Genetic Diseases Program. Connecticut Dept. of Health, Maternal & Child Health Div. 1984; 1-10.
- Bergler JH. Development of Increased Financial Support for Genetics Services. Washington, D.C.: Dept. of Health Care Administration, George Washington University. 1979.
- Blatt R. What Are Your Clients Reading? *The Genetic Resource*. 1985-86; 2:41-4.
- Brelsford G. The Impacts of Alternative Funding Policies for Ambulatory Care Services on Hospitalization in the Indian Health Service Contract. *Alaska Med*. 1985; 27;2:31-5.
- Buyse ML E. Blue Cross/Blue Shield of Indiana Provides Reimbursement for BDIS. Center for Birth Defects Information Services, Boston: March of Dimes. 1983; 8.
- Collins DL. Perspectives in Genetic Counseling. National Society of Genetic Counselors, Inc. June 1986; 8;2:1-5.
- Comptroller General of the United States. Maternal and Child Health Block Grant: Program Changes Emerging Under State Administration. Report to Congress GAO/HRD-84-35. 1984.
- Dievler A. Legislative Update. *The Genetic Resource*. 1985-86; 2:33-5.
- Ford LC. The Future of Pediatric Nurse Practitioners. *Pediatrics*. 1979; 64:113-14.
- The Genetic Resource*. An Updated Directory of Comprehensive Genetic Centers Within Massachusetts. *The Genetic Resource*. 1985-86; 2:45-6.
- The Genetic Resource*. In Vitro Fertilization Programs in Massachusetts. *The Genetic Resource*. 1985-86; 2:4-7.
- Greenstein RM. Clinical Genetics Programs and Service Reimbursement. New England Regional Genetics Group Meeting Presentation. 1981; 1-6.
- Greenstein RM. Third Party Reimbursement. 1-4.
- Greenstein RM, Abuelo D, Goodmay L. Report of Third Party Payment Committee. Feasibility Study for Enhanced Regionalization of Genetic Services in New England, Durham, NH. Nov. 1979; 1-5.
- Griffin M. Emotional Aspects of Infertility: A Public Health Concern. *The Genetic Resource*. 1985-86; 2:1-4.
- Holtzman NA. The Impact of the Federal Cutback on Genetic Services. *Am J Med Gen*. 1983; 15:353-65.
- Hudson RB. A Block Grant to the States for Long-Term Care. *J Health Polit, Polic & Law*. 1981; 6:9-28.
- Iowa Birth Defects Advisory Committee. Regional Genetic Consultation Service Patient Fees. MCH Div. of the Iowa State Dept. of Health. 1983; 1-10.
- Kahn L. The Influence of Funding on the Future of Pediatric Nurse Practitioner Programs. *Pediatrics*. 1979; 64:106-10.
- Kelly TE. Essentials of Genetic Counseling (Part 1). *Hospital Medicine*. 1985; 110-32.
- Kelly TE. Essentials of Genetic Counseling (Part 2). *Hospital Medicine*. 1985; 94-116.
- Lis EF. Children's Home Health Network of Illinois (CHHNI). Personal Communication. Univ of IL at Chicago. 1985; 1-2.
- Meyers TL, Prouty LA. Survey of Costs of Genetics Services. Johnson City, TN: Department of Pediatrics, East Tennessee State University. 1984.
- Newacheck PW. Reimbursement for Chronically Ill Children (SPRANS). Personal Communication, Univ. of Calif, San Francisco. 1985; 1-24.
- Omenn GS, Nathan RP. What's Behind Those Block Grants in Health? *N Engl J Med*. 1982; 306:1057-60.
- Rollnick BR. A Time Analysis of a Genetic Counseling Delivery System. *Birth Defects*. 1984; 20:208-12.
- Select Panel for the Promotion of Child Health. Better Health for our Children: A National Strategy. U.S. Dept. of Health & Human Serv, Public Health Serv. DHHS (PHS)#79-55071. 1981; II:111-126.
- Sepe SJ, Marks JS, Oakley GP, et al. Genetic Services in the United States. *JAMA*. 1982; 248:1733-5.
- Siminovich L, Banister P, Byles JA, et al. Genetic Services. The Ontario Council of Health. Toronto, Ontario. 1976.
- Stephen R, Amato S. Council of Regional Networks for Genetic Services. Morgantown, WV: Department of Pediatrics, West Virginia University. 1985.
- U.S. Bureau of Human Services. The Impact of the MCHS Block Grant on Genetic Diseases. U.S. Division of MCH, Genetic Section. 1982; 1-16.
- U.S. Department of Health E. A.W. The Development of Legislation and Regulation for PKU Screening. Genetic Screening for Inborn Errors of Metabolism. DHEW Publication No. (MSA)77-5124. pp44-87.
- Working Committee on Genetic Associate Support. Sources of Support for Genetic Associates. National Meeting on Genetic Counseling, Williamsburg, VA. 1979; 1-4.



## **B. Secondary References—Genetic Funding**

- Bernhardt BA, Weiner J, Foster EC, et al. A Time Analysis of Clinical Genetics Services. American Society of Human Genetics 37th Annual Meeting. Nov. 1986; A51.
- Clow CL. Genetic Services in Canada: The View from Medicare. Human Genetics, Part B: Medical Aspects. 1982; 389-98.
- The Division of Medical Genetics J.H.M.I. Economic Aspects of Clinical Genetics Services. Genetic Disease Services Branch, Division of Maternal and Child Health. May 1-2, 1986; 1-14.
- Frezal J, Deboise J. Relance de la Prevention Perinatale en Mutualite Sociale Agricole. Arch Fr Pediatr. 1984; 41:655-8.
- Greenstein RM, Gardiner GB. Cost Containment and Genetics Services: Defining Comprehensive Genetics Centers for Reimbursement. ASHG 37th Annual Meeting. 1986; A63.
- Kloza EM. Third Party Payment for Genetic Services. Maine Assoc, Hu Gen News Bulletin. 1983; 6:1-2.
- Leyland AF, Carroll MY, Kaplan GN. Health Services Foundation. Final Report Genetics Services Benefit Study. BC & BS, 676 N. St. Clair St. Chicago IL 60611. 1983; 1-87.
- Massachusetts Department of Public Health. Cost-Benefit Analysis of Newborn Screening for Metabolic Disorders. N Eng J Med. 1974; 291:1414-6.
- Nelson WB, Swint JM, Caskey CT. An Economic Evaluation of a Genetic Screening Program for Tay-Sachs Disease. Am J Hum Genet. 1978; 30:160-6.
- Normal C, Marshall E. Boom and Bust in Biotechnology. Science. 1982; 216:1076-82.
- Norman C. First Casualty in the Biotechnology Derby. Science. 1981; 213:1087-90.
- President's Commission for the Study of Ethical Problems in Medicine, and Biomedical and Behavioral Research. The Evolution and Status of Genetic Services. Genetic Screening and Counseling. 198 ; U.S. Government Printing Office:9-39.
- Rollnick BR. A Time Analysis of a Genetic Counseling Delivery System. Birth Defects. 1984; 20:6:208-212.
- Smith PS, Keyes NC, Forman EN. Socioeconomic Evaluation of a State-Funded Comprehensive Hemophilia-Care Program. N Eng J Med. 1982; 306:575-9.
- Swint JM, Shapiro JM, Corson VL, et al. The Economic Returns to Community and Hospital Screening Programs for a Genetic Disease. Preventive Med. 1979; 8:463-70.
- Univ. Affiliated Fac., Rose F. Kennedy Ctr. Albert Einstein Coll. of Med. Health Financing for Chronically Ill & Disabled Children: Developing the Data Base & Policy Proposals. Yeshiva Univ, Ben. Cardozo Sch. of Law & A. Einstein Col. of Med. 1984; 1-25.
- Vogt BL, Librizzi RJ, Weiner S. Prenatal Testing Referrals of Patients Calling Teratogen Information Programs: Impact and Income. Teratology Society 26th Annual Meeting. July 1986; P95C.
- Weber BS. Proposed Criteria for Participation of Provid. & Recip., & for the Inclusion of Serv. in the Project to Expand the Title XIX Fam. Plan. Prog. to Incl. Genetic Serv. Texas Dept. of Human Resources, Fam. Plan. Div. 1979; 1-4.
- Williams JK, Rehling E, Clark M. Licensure and Genetic Counseling. Perspectives in Genetic Counseling. 1985; 7:1-3.

## CATEGORY 8—HEALTH INSURANCE (COMMERCIAL)

### A. Primary References

- Associated Press. Blue Cross May Not Deserve Tax Break, Auditors Report. *Hartford Courant*. July 28, 1986.
- Austin G. Child Health-Care Financing and Competition. *N Engl J Med*. 1984; 311:1117-20.
- Beadle CE. Saving the FSA'Flex' can—and should—survive tax changes. *Business Insurance*. April 1, 1985; 25-6.
- Brailey AG. The Promotion of Health Through Health Insurance. *N Engl J Med*. 1980; 302:51-52.
- Butler JA, Singer JD, Palfrey JS, et al. Health Insurance Coverage and Physician Use Among Children With Disabilities: Findings From Probability Samples in Five Metropolitan Areas. *Pediatrics*. Jan. 1987; 79:1:89-98.
- Danks DM. Blame, Compensation and Birth Defects. *Med J Australia*. 1985; 143:135-6.
- Delbanco TL, Meyers KC, Segal AB and EA. Paying the Physicians Fee-Blue Shield and the Reasonable Charge. *N Engl J Med*. 1979; 301:1314-20.
- Durenberger. S 2403. U.S. Congressional Record. 1986.
- Farley PJ. Private Health Insurance in the United States. DHHS Publication No. (PHS)86-3406. September 1986; 1-106.
- Freedman SA. Megacorporate Health Care—A choice for the Future. *N Engl J Med*. 1985; 312:579-82.
- Geisel J. Insurers Protest State-mandated Health Benefits. *Business Insurance*. March 4, 1985; 3,43.
- Gerber P. Blame, Compensation and Birth Defects—Letter to the Editor. *Med J Australia*. 1985; 143:477-8.
- Health Cost Management Resource Center. C. Business Coalition on Health. Flexible Spending Accounts. Internal Revenue Code Section 125. Proposed Regulations. May 1984; 124.
- Health Insurance: How to Determine Adequate Coverage. The Book of, Inside Information. Boardroom Books. 1986; 428-33.
- Health Law Digest. Uninsured Welfare Benefit Plan Not Subject To State Insurance Law. *Health Law Digest*. 1986; 14:16.
- Kastiel DL. Insurers, Consultants Oppose Bill Forcing Well-Child Coverage. *Business Insurance*. April 1, 1985; 3-12.
- Kennedy, Hatch. Bill S.1793—Alternatives to Hospitalization for Medical Technology Dependent Children Act of 1985. 99th Congress, 1st Session. 1985; 11.
- Kunz (Ed). AMA Family Medical Guide. Random House Publications. 1982; 739-53.
- Letter to the Editor. Bagshawe KD. How Much Can the NHS Afford to Spend to Save a Life or Avoid a Severe Disability? *Lancet*. 1985; i:80.
- Letter to the Editor. MacGregor JE. How Much Can the NHS Afford to Spend to Save a Life or Avoid a Severe Disability? *Lancet*. 1985; 1:80.
- Letter to the Editor. Path M, Leck I. How Much Can the NHS Afford to Spend to Save a Life or Avoid a Severe Disability? *Lancet*. 1985; 1:80.
- Melcher Jr. GW, Berini RY. A Perspective of Insurance Coverage for Genetic Disorders. Washington, D.C.: National Genetics Foundation. 1978.
- Meotti MP. Connecticut State Legislature Insurance Coverage Mandates. Personal Communication. 1985; 1-3.
- O'Malley D, Schiessman S, Doty K. Insurance Marketing By the Health Profession. American Hospital Association National Meeting. Nov. 1984.
- Pappas N, McGraw M. Companies Revise Health Coverage. *Hartford Courant*. Aug 11, 1985; 1, A16-17.
- Parver AK. Third-Party Payment for Nutrition Care Services. *JAMA*. 1984; 84:693-700.
- Pediatric News. Health Care Needs of Children Said to Have Fallen Through Third-Party Coverage Net. *Pediatric News*. 1986; 20:3.
- Pediatric News. Revolution is Reducing Health Care to a Market Commodity. *Pediatric News*. May, 1986; 20:4.
- Roberts CJ, Farrow SC, Charny MC. How Much Can the NHS Afford to Spend to Save a Life or Avoid a Severe Disability? *Lancet*. 1985; 1:89-91.
- Siu AL, Sonnenberg FA, Manning WG, et al. Inappropriate Use of Hospitals in a Randomized Trial of Health Insurance Plans. *N Engl J Med*. 1986; 315:1259-66.
- Smits H, Draper P. Care of the Aged: An English Lesson? *Annals of Internal Medicine*. June 1974; 80:6:747-53.
- U.S. Dept. of HEW. Disability Insurance. Washington, D.C.: Alcohol, Drug Abuse & Mental Health Administration. 1975; Publication NO. (ADM) 76-287.
- Valdez RB, Leibowitz A, Ware JE, et al. Health Insurance, Medical Care, and Children's Health. *Pediatrics*. 1986; 77:124-28.
- Wald N, Oppenheimer. Letter to the Editor. How Much Can the NHS Afford to Spend to Save a Life or Avoid a Severe Disability? *Lancet*. 1985; 1:80.
- War JE, Brook RH, Rogers WH, et al. Comparison of Health Outcomes at a Health Maintenance Organization With Those of Fee-For-Service Care. *Lancet*. May 1986; 1017-22.

Washington Press. CHAMPUS to Be Converted From Fee-For-Service Plan. Pediatric News. July 1986; 20;7:15.  
Wrenn K. No Insurance, No Admission. N Engl J Med. 1985; 312:373-4.

#### **B. Secondary References—Health Insurance (Commercial)**

- Abrams S, Wassel N. Health-Care Crisis Won't Cure Itself. *The Hartford Courant*. Dec. 3, 1986.
- Berkowitz M. Social Insurance and Rehabilitation—The Netherlands, Sweden, Finland and Israel. Fellowship Report, World Rehabilitation Fund. 1985; 53.
- Brink SD. Healthcare in the 1990s: A Buyer's Market. *Hosp Management Rev*. 1986; 4.
- Buyse ML E. Blue Cross/Blue Shield of Indiana Provides Reimbursement for BDIS. Center for Birth Defects Information Services, Boston: March of Dimes. 1983; 8.
- Cable RG., Saxton P, Rickles F, Katz AJ. Home Shipment of Coagulation Factor Concentrated by a Regional Blood Center. Analysis of 5 year's Experience. American National Red Cross. 1984; 1-28.
- Colburn D. How many aren't covered? The equivalent of the nation's 36 largest cities. *Washington Post*. July 21, 1986; 11-3.
- Curtis R. The Role of State Governments in Assuring Access to Care. *Inquiry*. Fall 1986; 23:277-85.
- Darling H. The Role of the Federal Government in Assuring Access to Health Care. *Inquiry*. Fall 1986; 23:286-95.
- Durenberger, Kennedy, Heinz, Riegle. Bill S.2403—A Bill to Amend the Internal Revenue Code of 1954 to Assure Access to Health. 99th Congress, 2nd Session. 1986; 132.
- Fein R. Effects of Cost Sharing in Health Insurance. *N Engl J Med*. 1981; 305:1526-28.
- Grazier KL, Richardson WC, Martin DP, et al. Factors Affecting Choice of Health Care Plans. *Health Services Research*. 1986; 29:659-82.
- International Medical News Service. Health Care Needs of Children Said to Have Fallen Through Third-Party Coverage Net. *Pediatric News*. 1986; 20:1:3.
- Johns L, Derzon RA, Anderson MD. Selective Contracting in California: Early Effects and Policy Implications. *Inquiry*. Spring 1985; 22:24-32.
- Kahn CR. A Proposed New Role for the Insurance Industry in Biomedical Research Funding. *N Engl J Med*. 1984; 310:257-8.
- Kaplan G. The Blue Cross and Blue Shield Association's Genetic Services Benefit Study. *Birth Defects*. 1984; 20;6:53-57.
- Krueger F. Bill would pay nurses in 'expanded role'. *Boston Hosp News*. Jan. 1987; 6.
- Leichter SB. Third Party Reimbursement: An Alternate Approach. *The Diabetes Educator*. Fall 1983; 32-3.
- Marquis MS. Consumers' Knowledge about Their Health Insurance Coverage. *Health Care Financing Review*. 1983; 5:65-80.
- McKie D. Commentary from Westminster: How Badly is the NHS doing Out of Private Practice? *Lancet*. June 1986; 1451-2.
- McNamara DG, Latson LA. Long-Term Follow-Up of Patients with Malformations for Which Definitive Surgical Repair Has Been Available for 25 Years or More. *Am J Cardiol*. 1982; 50:560-8.
- Meiners MR. The State of the Art in Long-Term Care Insurance. U.S. Department of Health and Human Services. April 1984; 1-34.
- Meiners MR, Trapnell GR. Long-term Care Insurance—Premium Estimates for Prototype Policies. *Medical Care*. Oct. 1984; 22;10:901-11.
- Mid-Atlantic Regional Human Genetic Network. Minimum Data Set. Mid-Atlantic Regional Human Genetic Network.
- Monheit AC, Hagan MM, Ber ML, et al. Health Insurance For The Unemployed: Is Federal Legislation Needed? *Health Affairs*. Spring 1984; 3;1:101-11.
- Newhouse JP, Manning WG, Morris CN, et al. Some Interim Results from a Controlled Trial of Cost Sharing in Health Insurance. *N Engl J Med*. 1981; 305:1501-7.
- Parker AK. Third-Party Payment for Nutrition Care Services. *J Am Dietetic Assoc*. 1984; 84:693-700.
- Rosenthal A. Care of the Postoperative Child and Adolescent with Congenital Heart Disease. *Advances in Pediatrics*. 1983; 30:131-67.
- Watkins PJ. ABC of Diabetes—Practical Problems. *Brit Med J*. 1982; 285:866-7.

## **CATEGORY 9—HEALTH MAINTENANCE ORGANIZATIONS (HMOs) and INDIVIDUAL PHYSICIAN ASSOCIATIONS (IPAs)**

### **A. Primary References**

- Anderson GF, Studnicki J. Insurers Competing with Providers. Hospitals. Dec 1, 1985; 64-6.
- Baldwin MF. Boston HMOs Ready for Stepped-up Battle. Modern Healthcare. May 10, 1985; 42-6.
- de Lissovoy G, Rice T, Ermann D, et al. Preferred Provider Organizations: Today's Models and Tomorrow's Prospects. Inquiry. Spring 1986; 23:7-15.
- DesHarnais SI. Enrollment in and disenrollment from health maintenance organizations by Medicaid recipients. Health Care Financing Review. Spring 1985; 6:3:39-50.
- Egdahl RH, Taft CH. Financial Incentives to Physicians. N Engl J Med. July 1986; 315:1:59-61.
- England WL. Setting health maintenance organization capitation rates for Medicaid in Wisconsin. Health Care Financing Review. Summer 1986; 7:4:67-74.
- Ermann D. Health Maintenance organizations: the future of the for-profit plan. JACM. 1986; 9:2:72-84.
- Fischer LA. Health Maintenance Organizations and the Medicare Program. J Florida M A. 1985; 72:777-9.
- Fisher L, Rowley PT, Lipkin Jr. M. Genetic Counseling for Beta-Thalassemia Trait Following Health Screening in an HMO: Comparison of Programmed and Conventional Counseling. Am J Hum Gen. 1981; 33:987-94.
- Fuerst ML. PPOs—To Join or Not To Join. Genetics. July 1985; 44-52.
- Hamilton RA. Six HMO's Apply to State in a Wave. Harford Courant. Aug. 3, 1986.
- Hoft RH, Glaser RJ. The Problems and Benefits of Associating Academic Medical Centers with Health-Maintenance Organizations. N Engl J Med. 1982; 307:1681-9.
- Hospital Management Review. HMO Dissatisfaction Increasing, Says HMO/PPO Expert; Are 'Preferred Supplier' Networks Next? Hosp Management Rev. 1986; 5:4-5.
- LeBrun P. Payers Step Up Roles in Discharge Planning. Hospitals. 1985; 98-102.
- Letter to the Editor. Resnick GD. Testing in Prepaid Versus Fee-For-Service Group Practices. N Engl J Med. 1986; 315:1295.
- Magnusson PR. An Anatomy of HMOs: Exploring the Remarkable Growth of HMOs in Massachusetts. Massachusetts Med. May/June 1986; 22-28.
- Manning WG, Leibowitz A, Goldberg GA, Rogers J, Newhouse JP. A Controlled Trial of the Effect of a Prepaid Group Practice on use of Services. N Engl J Med. 1984; 310:1505-10.
- Mayer TR, Mayer GG. HMOs: Origins and Development. N Engl J Med. 1985; 312:590-594.
- Pediatric News. Physicians Becoming More Supportive of Prepaid Health Plans. Pediatric News. Aug 1985; 19:7.
- Silber F. HMOs and Care of the Chronically Ill. Hospital Practice. June 1986; 13.
- Steinwachs DM, Weiner JP, Shapiro S, et al. A Comparison of the Requirements for Primary Care Physicians in HMOs with Projections Made by the GMENAC. N Engl J Med. 1986; 314:217-22.
- Stevens C. What's Happened to Those Big Prepaid-Care Savings? Hosp Management Rev. 1986; 5:9.
- Taylor H, Kagay M. The HMO Report Card: A Closer Look. Hosp Management Rev. 1986; 5:8.
- Wright CH, Gardin TH, Wright CL. Obstetric Care in a Health Maintenance Organization and a Private Fee-for-Service Practice: A Comparative Analysis. Am J Obstet Gynecol. 1984; 149:848-56.

**B. Secondary References—Health Maintenance Organizations (HMOs) and Individual Physician Associations (IPAs)**

Associated Press. Plan Would Let Medicare Recipients Join HMOs. Hartford Courant. May 23, 1984.

Health Insurance: How to Determine Adequate Coverage. The Book of, Inside Information. Boardroom Books. 1986; 428-33.

Ware JE, Brook RH, Rogers WH, et al. Comparison of Health Outcomes at a Health Maintenance Organization With Those of Fee-For-Service Care. Lancet. May 1986; 1017-22.

Washington Press. CHAMPUS to Be Converted From Fee-For-Service Plan. Pediatric News. July 1986; 20;7:15.



## CATEGORY 10—INTERNATIONAL ISSUES

### A. Primary References

- Berkowitz M. Social Insurance and Rehabilitation—The Netherlands, Sweden, Finland and Israel. Fellowship Report, World Rehabilitation Fund. 1985; 53.
- Cereseto S, Waitzkin H. Economic Development, Political-Economic System, and the Physical Quality of Life. *Am J Public Health*. June 1986; 76:661-66.
- Dagenais DL, Courville L, Dagenais MG. A Cost-Benefit Analysis of the Quebec Network of Genetic Medicine. *Soc Sci Med*. 1985; 20:601-7.
- Elling RH. The Capitalist World-System and International Health. *Int J Health Serv*. 1981; 11:21-51.
- Foets M, Berghmans F, Janssens L. The Primary Health Care Project in Belgium: A Survey on the Utilization of Health Services. *Soc Sci Med*. 1985; 20:181-90.
- Frezal J, Deboise J. Relance de la Prevention Perinatale en Mutualite Sociale Agricole. *Arch Fr Pediatr*. 1984; 41:655-8.
- Fuhrmann W, Weitzel HK. Maternal Serum Alpha-fetoprotein Screening for Neural Tube Defects. *Hum Gen*. 1985; 69:47-61.
- Hibbard BM, Roberts CJ, Elder GH, et al. Can We Afford Screening for Neural Tube Defects? The South Wales Experience. *Brit Med J*. 1985; 290:293-5.
- Hubbard R, Henifin MS. Genetic Screening of Prospective Parents and of Workers: Some Scientific and Social Issues. *Int J Health Services*. 1985; 15:231-51.
- Iglehart JK. Canada's Health Care System. *N Engl J Med*. July 1986; 315:3:202-8.
- Iglehart JK. Canada's Health Care System. *N Engl J Med*. Sept. 1986; 315:12:778-84.
- Jobert B. Populism and Health Policy: The Case of Community Health Volunteers in India. *Soc Sci Med*. 1985; 20:1-28.
- Kuzemko JA. Management of Partial Intestinal Obstruction in Cystic Fibrosis. *Lancet*. 1986; 326-8.
- Laberge C, Scriver CR, Clow CL, et al. Le Reseau de Medecine Genetique du Quebec: Un Programme Integre de Diagnostic, Conseil. *L'Union Medicale du Canada*. 1975; 104:428-32.
- Lancet. The Rand Health Insurance Study: A Spanner in the Works? *Lancet*. 1986; 1:1012.
- Lancet. Green-Paper on Primary Health Care: Implications for General Practice. *Lancet*. 1986; 1:1011-2.
- Lister J. Shattuck Lecture-The Politics of Medicine in Britain and the United States. *N Engl J Med*. July 1986; 315:3:168-73.
- Markova I, Forbes CD, Aledort LM, et al. A Comparison of the Availability and Content of Genetic Counseling as Perceived by Hemophilic Men and Carriers in the U.S.A., Canada, Scotland, and Greece. *Am J Med Gen*. 1986; 24:7-21.
- McKie D. Commentary from Westminster: How Badly is the NHS doing Out of Private Practice? *Lancet*. June 1986; 1451-2.
- Mehta L, Young ID. Attitudes of Asian Families to Genetic Counselling. *J Med Gen*. 1985; 22:413.
- Norgaard-Pedersen B, Bagger P, Bang J, et al. Maternal Serum—Alpha-fetoprotein Screening for Fetal malformations in 28,062 Pregnancies. *Acta Obstet Gynecol Scand*. 1985; 64:511-14.
- Passarge E, Vogel F. The Delivery of Genetic Counseling Services in Europe. *Human Genet*. 1980; 56:1-5.
- Poikolainen K, Eskola J. The Effect of Health Services on Mortality: Decline in Death Rates From Amenable and Non-Amenable Causes in Finland, 1969-81. *Lancet*. Jan. 1986; 199-202.
- Rhee S-O, Lyons TF, Payne BC, et al. USMGs Versus FMGs—Are There Performance Differences in the Ambulatory Care Setting? *Medical Care*. 1986; 24:248-58.
- Royston E, Ferguson J. The Coverage of Maternity Care: A Critical Review of Available Information. *Wld Hlth Statist Quart*. 1985; 38:267-88.
- Scott-Samuel A. Point of View Social Inequalities in Health: Back on the Agenda. *Lancet*. May 1986; 1084-6.
- Scul A. Deinstitutionalization and Public Policy. *Soc Sci Med*. 1985; 20:545-52.
- Wilcken B, Chalmers G. Reduced Morbidity in Patient with Cystic Fibrosis Detected by Neonatal Screening. *Lancet*. 1985; 1319-21.

## B. Secondary References— International Issues

- Banta D. The Uses of Modern Technologies: Problems and Perspectives for Industrialized and Developing Countries. *Bul Pan Am Health Organ.* 1984; 18:139-50.
- Barganier C, Henson JF, Finley WH. Genetic Counseling in Families at Increased Risk for Neural Tube Defects. *Am J Med Sci.* 1985; 22:301-4.
- Black M. Handicapped Children in a Developing Nation—Bangladesh. *Am J Occup Ther.* 1977; 31:499-504.
- Boppart I, Brock D, Dallaire I, et al. Maternal Serum Alpha-Fetoprotein Screening for Neural Tube Defects. *Prenatal Diagnosis.* 1985; 5:77-83.
- Buhler E. Genetic Screening of In Vitro Fertilization (IVF)—Embryo Transfer (ET) Patients. *Experientia.* 1985; 41:1494-5.
- Chan CK. Eugenics on the Rise: A Report from Singapore. *Int J Health Services.* 1985; 15:707-12.
- Dagenais DL, Courville L, Dagenais MG. A Cost-Benefit Analysis of the Quebec Network of Genetic Medicine. *Soc Sci Med.* 1985; 20:601-7.
- Danks DM. Blame, Compensation and Birth Defects. *Med J Australia.* 1985; 143:135-6.
- Gerber P. Blame, Compensation and Birth Defects—Letter to the Editor. *Med J Australia.* 1985; 143:477-8.
- Gerber P, Pearn JH, Bell J. Prenatal Cytogenetic Diagnosis: Some Potential Legal Implications. *Med J Australia.* 1985; 142:80-3.
- Greer DS. Editorial Draft. *Comparative Health System Newsletter.* Fall, 1986.
- Harper PS, Sarfarazi M. Genetic Prediction and Family Structure in Huntington's Chorea. *Brit Med J.* 1985; 290:1929-31.
- Haworth JC, Miller JR. Screening, Counselling and Treatment of Hereditary Metabolic Disease: A Survey of Resources in Canada. *CMAJ.* 1974; 111:1147-55.
- Heggenhougen HK. Will Primary Health Care Efforts Be Allowed To Succeed? *Soc Sci Med.* 1984; 19:217-24.
- Hill IR. Liability and In-Vitro Fertilization. *Med Sci Law.* 1985; 25:270-4.
- Lenke RR, Levy HL. Maternal Phenylketonuria and Hyperphenylalaninemia—An International Survey of the Outcome of Untreated and Treated Pregnancies. *N Eng J Med.* 1980; 303:1202-8.
- Light DW, Liebfried S, Tennstedt F. Social Medicine vs Professional Dominance: The German Experience. *Am J Public Health.* 1985; 75:78-83.
- Malastella G, Barlocco EG. Neonatal Screening for Cystic Fibrosis. *Lancet.* 1986; 1162-3.
- Mohan J, Woods KJ. Restructuring Health Care: The Social Geography of Public and Private Health Care Under the British Conservative Government. *Int J Health Serv.* 1985; 15:197-215.
- Myers TF, Ahmed GS, Anderson CL, et al. A Modification of the International Classification of Diseases for Uniform Coding of Diagnosis, Procedures, and Medications. *Am J Perinatol.* 1985; 2:240-1.
- Orsini A. Aspects Medico-Sociaux des Hemoglobinoses. *Arch Franc Ped.* 1977; 34:393-8.
- Pearce JM. The Use of Ultrasound in the Diagnosis of Congenital Anomalies. *Midwife Health Visitor & Community Nurse.* 1983; 19:82-8.
- Smith GP. Defective Newborns and Government Intermeddling. *Med Sci Law.* 1985; 25:44-8.
- Storhaug K. Aspects of Living Conditions Among Groups of Disabled Children and Their Families in Norway: Family Situation, Mothers' Health, Financial Assistance. *Soc Sci Med.* 1983; 17:1837-45.
- Takenaga N, Kai I, Ohi G. Evaluation of Three Cervical Cancer Detection Programs in Japan With Special Reference to Cost-Benefit Analysis. *Cancer.* 1985; 55:2514-19.
- Turnbull AC. Fetal Preventive Medicine. Birth Defects: Original Article Series. 1985; 21:37-54.
- Warsof SL, Rodeck CH. Fetoscopy. *Midwives Chronicle & Nursing Notes.* 1983; 194-5.
- World Health Organization. Report of WHO Advisory Group on Hereditary Diseases. World Health Organization. 1982; HMG/AG/82.4:17.

## CATEGORY 11—MEDICAID/MEDICARE

### A. Primary References

- Adreano R, Smolensky E, Helminiak T. The economics of information exchange: Medicaid in W'sconsin. *Health Care Financing Review*. Fall 1986; 8;1:65-78.
- Associated Press. Plan Would Let Medicare Recipients Join HMOs. *Hartford Courant*. May 23, 1984.
- Babbitt B. Medicare Coverage in Need of Treatment. *Hartford Courant*. Jan. 21, 1986; B9.
- Blendon RJ, Aiken LH, Freeman HE, et al. Uncompensated Care by Hospitals or Public Insurance for the Poor, Does It Make a Difference. *N Engl J Med*. May 1986; 314;18:1160-4.
- Blim RD, Austin G, Cooper LZ, et al. Medicaid Policy Statement. *Pediatrics*. May 1986; 77;5:762-3.
- Caring. Medicaid Coverage of the Pediatric Population. *Caring*. May 1985; 52.
- The Catholic Health Association's Task Force on Health Care of the Poor. No Room in the Marketplace, The Health Care of the Poor. The Catholic Health Association of the United States. St. Louis, MO. April 24, 1986; 1-59.
- Clow CL. Genetic Services in Canada: The View from Medicare. *Human Genetics, Part B: Medical Aspects*. 1982; 389-98.
- Cromwell J, Burstein P. Physician losses from Medicare and Medicaid discounts: How real are they? *Health Care Financing Review*. Summer 1985; 6;4:51-68.
- Curtis R. The Role of State Governments in Assuring Access to Care. *Inquiry*. Fall 1986; 23;277-85.
- Darling H. The Role of the Federal Government in Assuring Access to Health Care. *Inquiry*. Fall 1986; 23;286-95.
- Davidson SM. Physician Participation in Medicaid: Background and Issues. *J Health Polit, Polic & Law*. Winter 1982; 4:703-717.
- Davidson SM, Cromwell J, Schurman R. Medicaid Myths: Trends in Medicaid Expenditures and the Prospects for Reform. *J of Health Politics, Policy and Law*. Winter 1986; 10;4:699-728.
- Davidson SM, Herold TE, Simon MB. The Medical Care Advisory Committee for State Medicaid programs; Current status and trends. *Health Care Financing Review*. Spring 1984; 5;3:89-98.
- Davis C. Interview—Hospitals and PPS: Exemplary Beginnings. *Hospitals*. 1985; 96-7. Gold RB, Kenney AM. Paying for Maternity Care. *Family Planning Perspectives*. May/June 1985; 17;3:103-10.
- Guyer B. Children in a Changing Health Care System. Department of Maternal and Child Health. Harvard University School of Public Health. Feb. 23, 1987; 1-39.
- Health Care Financing Administration. U.S. Department of Health and Human Services. Federal Initiatives on Home Care Under the Medicaid Program. *Coalition Quarterly*. 1985; 10-11.
- Held PJ, Holahan J. Containing Medicaid Costs in a year of Growing Physician supply. *Health Care Financing Reviews*. 1985; 7;1:49-60.
- Holahan J. Paying for Physician Services. *Health Care Financing Review*. Spring 1984; 5;1:99-110.
- Jencks SF, Dobson A. Evaluation Options for Reforming Medicare's Physician Payment Process—Physician DRGs and Alternatives. (Draft Report). Health Care Financing Administration, Office of Research. 1984.
- Jencks S, Dobson A. Strategies for Reforming Medicare's Physician Payments. Physician Diagnosis-Related Groups and Other Approaches. *N Engl J Med*. June 6, 1985; 312;23:1492-1499.
- Joe T, Meltzer J, Farrow F. Restructuring Medicaid: An Agenda for Change, Executive Summary. The National Study Group on State Medicaid Strategies. Washington, D.C. 1986; 1-12.
- Johns L, Anderson MD, Derzon RA. Selective Contracting in California. Experience in the Second Year. *Inquiry*. Winter 1985; 22;335-47.
- Johns L, Derzon RA, Anderson MD. Selective Contracting in California. Early Effects and Policy Implications. *Inquiry*. Spring 1985; 22;24-32.
- Kennelly BB. A Family Guide to Medicare. Congresswoman Reports. Fall 1985.
- Kletke PR, Davidson SM, Perloff JD, et al. The Extent of Physician Participation in Medicaid: A Comparison of Physician Estimates and Aggregated Patient Records. *Health Services Research*. Dec. 1985; 20;5:503-23.
- Krischer JP, Cook BA. State and Federal Expenditures on Medicaid Eligible Chronically Ill Children in Rural Florida. *J Chron Dis*. 1985; 38;11:951-6.
- Leroux EA. One Way to Hold Down Medical Costs. *Hartford Courant*. Nov. 11, 1985.
- Lurie N, Ward NB, Shapiro MF, et al. Termination of Medical benefits—A Follow-up Study One Year Later. *N Engl J Med*. 1986; 314:1266-68.
- Melvitt R, Buczko W. Medicaid program characteristics: Effects on health care expenditures and utilization. *Health Care Financing Review*. Winter 1985; 7;2:1-29.
- Medicare Fee Reforms Considered. *Hartford Courant*. August 24, 1985; A4.
- Meltzer J. Reforming the Medicaid Program to Improve Access to Health Care Services. *Bull. N.Y. Acad. Med*. Jan./Feb 1986; 62;1:87-93.

- Mitchell JB, Schurman R. Access to Private Obstetrics/Gynecology Services Under Medicaid. *Medical Care*. Nov. 1984; 22;11: 1026-37.
- National Clearing House for Drug Abuse Information. Report Series 35, Issue A. U.S. Department of Health, Education and Welfare. August 1975; 1-39.
- New Jersey Department of Health. State Dept. of Health Takes Medicare to Court: At Issue: The Outpatient Waiver. *Healthline*. June, 1985; 1.
- Ortbals DW. Effect of Medicare/Medicaid Reimbursement Policies on Diagnostic Methodology in the Physician's Office. *Diagn Microbiol Infect Dis*. 1986; 143S-150S.
- Pappas N. Plan Tries to Better Care Under Medicaid. *Hartford Courant*. Apr 30, 1985; 1,7.
- Pappas N. Tighter Control Urged on Medicaid Program. *Hartford Courant*. Sept. 10, 1985.
- Medicaid/Medicare (Primary)
- Reeder CE, Nelson AA. The Differential Impact of Copayment on Drug Use in a Medicaid Population. *Inquiry*. Winter 1985; 22;396-403.
- Rymer MP, Ofsmann CG, Bailis LN, et al. Medicaid Eligibility; Problems and Solutions. Westview Press. Boulder, CO. 1979; 7-31.
- Schieber GJ, Burney IL, Golden JB, Knaus WA. Physician Fee Patterns Under Medicare: A Descriptive Analysis. *N Engl J Med*. 1976; 294:1089-1093.
- Schwartz HA. Billing Medicare, Medicaid. *Massachusetts Med*. July/August 1986; 15-17.
- Smits H, Feder J, Scanlon W. Medicare's Nursing-Home Benefit: Variations in Interpretation. *N Engl J Med*. Sept 30, 1982; 307:855-62.
- Weber BS. Proposed Criteria for Participation of Provid. & Recip., & for the Inclusion of Serv. in the Project to Expand the Title XIX Fam. Plan. Prog. to Incl. Genetic Serv. Texas Dept. of Human Resources, Fam. Plan. Div. 1979; 1-4.
- Winalen WA. Guide to Review Activities in PPSD Hospitals. Connecticut Peer Review Organization (CPRO). 1984; 1-28.
- Whitcomb ME. Health Care For The Poor; A Public-Policy Imperative. *The New Engl J of Med*. Nov. 1986; 315;19:1220-22.

#### **B. Secondary References—Medicaid/Medicare**

- American Society of Human Genetics. Genetic Services Committee. Report on Cost and Genetic Services. 1985; 1-6.
- Camerson JM. The Indirect Costs of Graduate Medical Education. *N Engl J Med.* 1985; 321:1233-38.
- Copeland NR. The Impact of DRG's in Hospitals in Delaware. *Del Med J.* 1986; 58:96-8.
- Council on Maternal and Child Health. Background Paper on Universal maternity Care. *J Publ Health Policy.* 1986; 105-23.
- DesHarnais SI. Enrollment in and disenrollment from health maintenance organizations by Medicaid recipients. *Health Care Financing Review.* Spring 1985; 6;3:39-50.
- England WL. Setting health maintenance organization capitation rates for Medicaid in Wisconsin. *Health Care Financing Review.* Summer 1986; 7;4:67-74.
- Fischer LA. Health Maintenance Organizations and the Medicare Program. *J Florida M A.* 1985; 72:777-9.
- Gordon T, DeAngelis C, Peterson R. Capitation Reimbursement for Pediatric Primary Care. *Pediatrics.* 1986; 77:29-34.
- Health Systems Agency of North Central Connecticut. A Managed Health Care Program for Hartford's Low Income Population. Hartford, CT: HSA North Central CT. 1984.
- May DP. The Privileged Must Help Cover Hospital Costs of Poor, Elderly. *Hartford Courant.* June 28, 1986; D11.
- Meiners MR, Coffey RM. Hospital DRGs and the Need for Long-Term Care Services: An Empirical Analysis. *Health Services Research.* August 1985; 20;3:359-84.
- Mitchell JB, Schurman R. Access to Private Obstetrics/Gynecology Services Under Medicaid. *Medical Care.* Nov. 1984; 22;11:102—6-37.
- Pediatric News. U.S. Budget Cuts Said to Affect Child Health.
- Pediatric News. Oct 1985; 19:22.
- Somer AR. Why Not Try Preventing Illness as a Way of Controlling Medicare Costs? *N Engl J Med.* 1984; 311:853-856.

## CATEGORY 12—NEW TECHNOLOGIES

### A. Primary References

- Abuelo D, Bowers GB, Haddad V. Genetic Counseling for Low Maternal Serum alpha-fetoprotein- Letter to the Editor. *American J. Obstet. Gynecol.* Jan. 1985; 151:1:147.
- Anderson WF. Human Gene Therapy: Scientific and Ethical Considerations. *Recombinant DNA Tech Bull.* 1985; 8:55-63.
- Anionwu EN. Sickle Cell Disease: Screening and Counselling in the Antenatal and Neonatal Period—Part 2. *Midwife Health Visitor & Community Nurse.* 1983; 19:440-3.
- Anionwu EN. Sickle Cell Disease: Screening and Counselling in the Antenatal and Neonatal Period—Part 1. *Midwife Health Visitor & Community Nurse.* 1983; 19:402-6.
- Asmusen MA, Clegg MT. Multiallelic Restriction Fragment Polymorphisms in Genetic Counseling: Population Genetic Consideration. *Hum Hered.* 1985; 35:129-42.
- Banta D. The Uses of Modern Technologies. Problems and Perspectives for Industrialized and Developing Countries. *Bul Pan Am Health Organ.* 1984; 18:139-50.
- Banta D. Technology—Review of Medical Technology Policies Shows Need, Opportunities for Changes. *Hospitals.* Apr. 1, 1982; 87-90.
- Beech BA. Consumer View of Randomized Trials of Chorionic Villus Sampling. *Lancet.* 1986; 1157.
- Behney C, Banta D. Is Medical Technology Safe? *Hospitals, JAHA.* June 1979; 110-12.
- Bernard J. Economic and Moral Consequences of Medical Progress. *Revue Medical Suisse Rommande.* 1982; 102:83-93.
- Biotechnology's Hype and Hubris. *The Economist.* April 19, 1986; 96-7.
- Blank RH. Public Policy Implications of Human Genetic Technology: Genetic Screening. *J Med Phil.* 1982; 7:355-74.
- Brent RL. Ultrasonography in Fetal Diagnosis. *Ped Ann.* 1981; 10:2:49-60.
- Buhler E. Genetic Screening of In Vitro Fertilization (IVF)-Embryo Transfer (ET) Patients. *Experientia.* 1985; 41:1494-5.
- Bunker JP, Fowles JJ, Schaffarzick R. Evaluation of Medical-Technology Strategies—Effects of Coverage and Reimbursement (First of Two Parts). *N Engl J Med.* 1982; 306:620-24.
- Business Weekly. Culture Club-Pharmaceuticals a Growth Industry In Connecticut. *Hartford Courant.* June 16-22, 1986.
- Chakravarti A, Buetow KH. A Strategy for Using Multiple Linked Markers for Genetic Counseling. *Am J Hum Gen.* 1985; 37:984-97.
- Clayton JF, Bhattacharya SS, Wright AF, Price WH. The application of restriction fragment length polymorphisms to genetics. *Clinical Genetics Society.* 141.
- Cowchock S, Jackson L. Use of Alpha-Fetoprotein for Diagnosis of Neural Tube and Other Anomalies. *Clin Obstet Gynaecol.* 1980; 7:83-102.
- Cox CL, Sullivan JA, Roghmann KJ. A Conceptual Explanation of Risk-Reduction Behavior and Intervention Development. *Nurs Res* 1984; 33:168-73.
- Edwards RG, Purdy JM, Walters WAW, et al. Human Conception in Vitro. Proceedings of the First Born Hall Meeting. *J. of Medical Ethics.* June 1984; 16:2:99.
- England WL, Roberts SD. Immunization to Prevent Insulin-Dependent Diabetes Mellitus? The Economics of Genetic Screening and Vaccination for Diabetes. *Annals of Internal Med.* 1981; 94:395-400.
- Feeny D, Tomkins DJ. Letter to the Editor: The Usefulness of Chromosome Banding in Pre and Postnatal Service Cytogenetics: A Reconsideration. *Am J Med Gen.* 1981; 9:79-87.
- Fisher NL, Starr ED, Greene T, Hoehn H. Utility and Limitations of Chromosome Banding in Pre and Postnatal Service Cytogenetics. *Am J Med Gen.* 1980; 5:285-94.
- Gardent H, Goujard J, Fardeau M, Crost M. Economics of the Diffusion of Prenatal Diagnosis by Amniocentesis, Part One: Epidemiologic, Medical, & Socioeconomic Bases. *Revue Epidemiol Sante Publique.* 1984; 32:88-96.
- Gardent M, Fardeau M, Lanoe JL, Kerleau M. Econ. of the Diffusion of Prenatal Dx by Amnio. Part Two: Facil. Decision Making in the Field of Pub. Health: Toward an Optimal Diff. *Revue Epidemiol Sante Publique.* 1984; 32:97-106.
- Herrmann J, Thomas E. Transabdominal Chorionic Villus Sampling as an Office Procedure. *Lancet.* 1986; 747.
- Holtzman NA. Pitfalls of Newborn Screening (With Special Attention to Hypothyroidism); When Will We Ever Learn? *Birth Defects: Original Article Series.* 1983; 19:111-20.
- Horwell DH, Loeffler FE. A New Approach to Antenatal Diagnosis. *Midwife Health Visitor & Community Nurse.* 1983; 19:396-8.
- Huether CA. Projection of Down's Syndrome Births in the United States 1979-2000, And the Potential Effects of Prenatal Diagnosis. *AJPH.* 1983; 73:1186-9.
- Iowa State Department of Public Health. Update on Newborn Screening. *Iowa Medicine.* 1986; 139-40.
- Jackson LG. First-Trimester Diagnosis of Fetal Genetic Disorders. *Hospital Practice.* 1985; 39-48.



- Jansen RPS. Sperm and Ova as Property. *J Med Ethics*. 1985; 11:123-6.
- Jolley I. Antenatal Screening for Fetal Abnormalities: Experiences in a District General Hospital. *Radiography*. 1983; 49:157-9.
- Kahn CR. A Proposed New Role for the Insurance Industry in Biomedical Research Funding. *N Engl J Med*. 1984; 310:257-8.
- Kasper AS. Maternal Serum Alpha Fetoprotein Testing: Some Public Policy Considerations. *Women-Health*. 1981; 6:147-53.
- Kaufmann CL, Williams PR. Fetal Surgery: The Social Implications of Medical and Surgical Treatment of the Unborn Child. *Women & Health*. 1985; 10:25-37.
- Khoury MJ, Newill CA, Chase GA. Epidemiologic Evaluation of Screening for Risk Factors: Application to Genetic Screening. *AJPH*. 1985; 75:1204-8.
- Korner H, Rodriguez L, Yero JLF. Maternal Serum Alpha-fetoprotein Screening for Neural Tube Defects and Other Disorders Using an Ultramicro-ELISA. *Hum Genet*. 1986; 73:60-3.
- Lancet. Can First-Trimester Fetal Diagnosis Be Reliably Evaluated? *Lancet*. 1985; 735-6.
- Lange K. Approximate Confidence Intervals for Risk Prediction in Genetic Counseling. *Am J Hum Gen*. 1986; 38:681-7.
- Lappe M. The New Technologies of Genetic Screening—The Predictive Power of the New Genetics. The Hastings Center Report. 1984; 18-21.
- Mastella G, Barlocco EG. Neonatal Screening for Cystic Fibrosis. *Lancet*. 1986; 1162-3.
- Michael CA. Routine Antenatal Screening. *Australian Family Physician*. 1985; 14:1195-9.
- Murray TH. The New Technologies of Genetic Screening—The Social Context of Workplace Screening. The Hastings Center Report. 1984; 21-3.
- Neufeld W. Bioengineering. The Promises and the Problems. Trend Analysis Program, American Council of Life Insurance. Jan. 1984; P1-27.
- NIH Director. ACTIONS. Recombinant DNA Technical Bulletin. 8:1:17-28.
- Nitowsky HM. Considerations on Informed Consent. An Office Guide to Prenatal AFP Screening. 1980; AFP Prenatal Screening Project, Foundation for Blood Research, Scarborough, Maine. 15-20.
- Normal C, Marshall E. Boom and Bust in Biotechnology. *Science*. 1982; 216:1076-82.
- Norman C. First Casualty in the Biotechnology Derby. *Science*. 1981; 213:1087-90.
- Person P-H, Kullander S. Long-term Experience of General Ultrasound in Pregnancy. *Am J Obstet Gynecol*. 1983; 146:942-47.
- Petitti DB. Competing Technologies: Implications for the Costs and Complexity of Medical Care. *N Engl J of Med*. Dec. 1986; 315:23:1480-3.
- Rogghmann KJ, Doherty RA. Reassurance Through Prenatal Diagnosis and Willingness to Bear Children After Age 35. *AJPH*. 1983; 73:760-2.
- Romeo A, Wagner J, Lee R. Prospective Reimbursement and the Diffusion of New Technologies in Hospitals. *Journal of Health Economics* 3. 1984; 1-24.
- Rosenfeld A. At Risk for Huntington's Disease. Who Should Know What and When? The Hastings Center Report. 1984; 5-8.
- Rowley PT, Fisher L, Lipkin Jr. M. Incorporation of Screening and Genetic Counseling for Beta-Thalassemia Trait into Primary Health Care: Effects on Knowledge & Attitudes. *Birth Defects:Original Article Series*. 1982; 18:231-241.
- Rowley PT, Loader S, Walden ME. Toward Providing Parents the Option of Avoiding the Birth of the First Child with Cooley's Anemia: Response to Hemoglobinopathy. *Ann NY Acad Sci*. 1985; 445:408-16.
- Scriver CR, Bardanis M, Cartier L, et al. Beta-Thalassemia Disease Prevention: Genetic Medicine Applied. *Am J Hum Gen*. 1984; 36:1024-38.
- Selle HF, Holmes DW, Ingbar ML. The Growing Demand for Midtrimester Amniocentesis: A Systems Approach to Forecasting the Need for Facilities. *AJPH*. 1979; 69:574-80.
- Smits H. The Clinical Context of Technology Assessment. *Journal of Health Politics, Policy & Law*. Spring 1984; 9:1:31-40.
- Stewart N. Women's Views of Ultrasonography in Obstetrics. *Birth*. 1986; 13:39-43.
- Super M, Swindlehurst C. Isoelectric Focusing of Serum in Genetic Counselling of Families With Cystic Fibrosis. *Am J Med Gen*. 1984; 18:449-453.
- Thom H, Campbell AGM, Farr V, et al. The Impact of Maternal Serum Alpha Fetoprotein Screening on Open Neural Tube Defect Births in North-East Scotland. *Prenatal Diag*. 1985; 5:15-19.
- Vogt BL, Librizzi RJ, Weiner S. Prenatal Testing Referrals of Patients Calling Teratogen Information Programs: Impact and Income. Teratology Society 26th Annual Meeting. July 1986; 95C.
- Vogt BL, Zuber C, Librizzi RJ. Time Intensity of Patient Calls to a Teratogen Information Program. Teratology Society 26th Annual Meeting. July 1986; 95C.

Wallace DL. Congress Examines Ethical Issues Given Birth by Genetic Engineering. Modern Healthcare. 1984; 114-6.  
Weitzel H. Alpha-Fetoproteins in Obstetrics. Gynakologe. 1983; 16:148-54.  
Wood C. Get Ready for Bioengineering. The Bangor (ME) Daily News. April 7, 1984; 19.

## **B. Secondary References—New Technologies**

- Anderson WF. Human Gene Therapy: Scientific and Ethical Considerations. *J Med & Philos.* 1985; 10:275-91.
- Banta D, Behney CJ. Medical Technology: Policies and Problems. *HCM Review.* Fall 1980; 45-52.
- Berg K, Fletcher J. Ethical and Legal Aspects of Predictive Testing. *Lancet.* 1986; 1:1043.
- Canter EF. Employment Discrimination Implications of Genetic Screening in the Workplace under Title VII and the Rehabilitation Act. *Am J Law and Med.* 1984; 10:323-47.
- Chamberlain J. The Benefits and Costs of Prenatal Diagnosis (Editorial). *Revue Epidemiol Sante Publique.* 1984; 32:85-87.
- Deitch R. Research on Embryos. *Lancet.* 1985; 469.
- Faden RR, Chwalow AJ, Orel-Crosby E, et al. What Participants Understand About a Maternal Serum Alpha-Fetoprotein Screening Program. *AJPH.* 1985; 75:1381-4.
- Fibison WJ, Davies BL. Dilemmas in Prenatal Diagnosis: A Case Study. *Issues in Health Care of Women.* 1983; 4:57-67.
- Finley WH, Finley SC. The Diagnosis of Genetic Disorders Before Birth. *Southern Med J.* 1976; 69:1486-92.
- Goldsmith J. 2036: A Health Care Odyssey. *Hosp Management Rev.* 1986; 5:1.
- Grace HJ. Prenatal Screening for Neural Tube Defects in South Africa—an Assessment. *So Af Med J.* 1981; 60:324-9.
- Green J. Detecting the Hypersusceptible Worker: Genetics and Politics in Industrial Medicine. *International J of Health Services.* 1983; 13:247-264.
- Greenstein RL. Controlling the Bugs—The First Decade in the Regulation of Biotechnology. *Applied Biochem Biotech.* 1985; 11:489-506.
- Hibbard BM. Screening for Neural Tube Defects. Results in Practice. *Midwife Health Visitor & Community Nurse.* 1982; 18:460-6.
- Hook EB, Schreinemachers DM. Trends in Utilization of Prenatal Cytogenetic Diagnosis by New York State Residents in 1979 and 1980. *AJPH.* 1983; 73:198-202.
- Jones JD. Screening Tests for Inherited Metabolic Diseases. *Mayo Clin Proc.* 1984; 59:347-9.
- Kuzemko JA. Management of Partial Intestinal Obstruction in Cystic Fibrosis. *Lancet.* 1986; 326-8.
- Lubs ML. Letter to the Editor: Cost Benefit Analysis in Genetic Disorders. *Am J Med Gen.* 1980; 6:331-32.
- Merz B. Markers for Disease Genes Open New Era in Diagnostic Screening. *JAMA.* 1985; 3153-9.
- Milewski E. Congressional Hearing on the Adequacy of Current Statutes and Scientific Knowledge for the Regulation of Biotechnology. *Recombinant DNA Tech Bull.* 1985; 8:7-16.
- Oberle I, Camerino G, Heilig R, et al. Genetic Screening for Hemophilia A (Classic Hemophilia) with a Polymorphic DNA Probe. *N Eng J Med.* 1985; 312:682-6.
- Pediatric News. Revolution is Reducing Health Care to a Market Commodity. *Pediatric News.* May, 1986; 20:4.
- Sadovnick AD, Baird PA. Maternal Age-Specific Costs of Detecting Down Syndrome and Neural Tube Defects. *Canadian J of Public Health.* 1982; 73:248-50.
- Schulman RM. Genetic Screening and the Law. *Medical Trial Technique Quarterly.* 295-303.
- Smits H, Draper P. Care of the Aged: An English Lesson. *Annals of Internal Medicine.* June 1974; 80:6747-53.
- Uzych L. Ethical Aspects of Predictive Testing. *Lancet.* 1986; 1445-6.
- Wilcken B, Chalmers G. Reduced Morbidity in Patient with Cystic Fibrosis Detected by Neonatal Screening. *Lancet.* 1985; 1319-21.

## CATEGORY 13—QUALITY CONTROL

### A. Primary References

- American Hospital Association. The Changing American Hospital. American Hospital Association. Chicago, Illinois.
- Boppart I, Brock D, Dallaire I, et al. Maternal Serum AlphaFetoprotein Screening for Neural Tube Defects. *Prenatal Diagnosis*. 1985; 5:77-83.
- Broder H, Trier WC. Effectiveness of Genetic Counseling for Families with Craniofacial Anomalies. *Cleft Palate Journal*. 1985; 22:157-62.
- Chapman S. What Are Your Odds in the Prenatal Gamble? *Leg Aspects of Med Prac*. Mar 1979; 30-6.
- Clayton EW. Legal Aspects of Medical Genetics in Wisconsin. *Wisconsin Med J*. 1985; 84:28-32.
- Dobson J, Koch R, Williamson M, et al. Cognitive Development and Dietary Therapy in Phenylketonuric Children. *N Eng J Med*. 1978; 278:1142-4.
- Dwyer JM. Scientific Criteria for Adopting Health Screening Measures. *Ped Nurs*. 1983; 9:195-7.
- Fallows J. The Case Against Credentialism. *The Atlantic Monthly*. December 1985; 49-67.
- Gonnella JS, Hornbrook MC, Louis DZ. Staging of Disease - A Case-Mix Measurement. *JAMA*. 1984; 251:637-46.
- Greenstein RL. Controlling the Bugs—The First Decade in the Regulation of Biotechnology. *Applied Biochem Biotech*. 1985; 11:489-506.
- Greenstein RM, Gardiner GB. Cost Containment and Genetics Services: Defining Comprehensive Genetics Centers for Reimbursement. *ASHG 37th Annual Meeting*. 1986; A63.
- Isele WP. Legal Aspects of Accreditation. *AAMC Committee on Education*. 1980; 4-7.
- Jones JD. Screening Tests for Inherited Metabolic Diseases. *Mayo Clin Proc*. 1984; 59:347-9.
- Kelly TE. Approaches to Clinical Diagnosis. *Clinical Genetics and Genetic Counseling*. 1980; Yearbook Medical Publishers, Inc., Chicago. 183-261.
- Milewski E. Congressional Hearing on the Adequacy of Current Statutes and Scientific Knowledge for the Regulation of Biotechnology. *Recombinant DNA Tech Bull*. 1985; 8:7-16.
- Patterson SP. Our Bundle of Responsibility. *Am J Obstet and Gyn*. 1984; 149:245-50.
- Smits H. The PSRO in Perspective. *N Engl J Med*. July 30, 1981; 305:253-59.
- Votava KM, Cleveland T, Hiltunen K. Home Care of the Patient Dependent on Mechanical Ventilation: Home Care Policy Development and Goal Setting Using Outcome Criteria for Quality Assurance. *Home Health Care Nurse*. 1985; 3:2:18-25.
- Williams JK, Rehling E, Clark M. Licensure and Genetic Counseling. *Perspectives in Genetic Counseling*. 1985; 7:1-3.
- Working Committee on Definition of Genetic Counseling. Definition of Genetic Counseling and the Role of the Genetic Counselor Trained at the Master's Level. *National Meeting on Genetic Counseling, Williamsbury, VA*. 1979; 1-2.

## B. Secondary References—Quality Control

- Beck HA. Consumer View of Randomized Trials of Chorionic Villus Sampling. *Lancet*. 1986; 1157.
- Behney C, Banta D. Is Medical Technology Safe? Hospitals, JAHA. June 1979; 110-12.
- Birth Defects Original Article Series. Toward More Effective Genetic Counseling. Birth Defects Original Article Series. 1981; 17:136-7.
- Childs B, Huether CA, Murphy EA. Human Genetics Teaching in U.S. Medical Schools. *Am J Hum Genet*. 1981; 33:1-10.
- Cohen DI. The Use of Prenatal Cytogenetic Diagnosis: A Comparison of Rates in Prepaid Group Practices and the General Population. *Medical Care*. 1980; 18:513-19.
- Coplan J. Wrongful Life and Wrongful Birth: New Concepts for the Pediatrician. *Pediatrics*. 1985; 75:65-72.
- Edwo EE, Seals BF, Kim J-O, et al. Factors Influencing Maternal Estimates of Genetic Risk. *Am J Med Gen*. 1985; 20:491-502.
- Epstein CJ, Childs B, Fraser FC, et al. Genetic Counseling. *Am J Hum Genet*. 1975; 27:240-2.
- Fisher L, Rowley PT, Lipkin Jr. M. Genetic Counseling for Beta-Thalassemia Trait Following Health Screening in an HMO: Comparison of Programmed and Conventional Counseling. *Am J Hum Gen*. 1981; 33:987-94.
- Freire-Maia N. Effects of Consanguineous Marriages on Morbidity and Preconscious Mortality: Genetic Counseling. *Am J Med Gen*. 1984; 18:401-6.
- Glendon M. Teaching Harry What We'd Thought He Knew. *Nursing85*. 1985; 44-6.
- Herrmann J, Thomas E. Transabdominal Chorionic Villus Sampling as an Office Procedure. *Lancet*. 1986; 747.
- Holt LH. DRGs (Diagnostic Related Groups): The Doctors' Dilemma. *Perspect Biol and Med*. 1986; 29:219-26.
- Holtzman NA. Pitfalls of Newborn Screening (With Special Attention to Hypothyroidism); When Will We Ever Learn? Birth Defects: Original Article Series. 1983; 19:111-20.
- Holzgreve B, Holzgreve W, Golbus MS. The relevance of preamniocentesis pedigree analysis and genetic counseling. *Clinical Genetics*. 1983; 24:429-433.
- Horn SD, Horn RA, Sharkey PD, et al. Misclassification Problems in Diagnosis-Related Groups. Cystic Fibrosis An Example. *N Engl J Med*. 1986; 314:484-87.
- Hospital Management Review. Can Hospitals Survive Under PPS and Maintain Quality of Care? *Hosp Management Rev*. 1986; 5.
- Ives EJ, Henick P, Morgan K, Holmes TM. Evaluation of Genetic Counseling following the birth of a Malformed newborn. *Genetics Abstract # 833:249A*.
- Kahkonen DM. DRG Impact on Medical Care. *Michigan Medicine*. 1985; 403.
- Kahn L. The Influence of Funding on the Future of Pediatric Nurse Practitioner Programs. *Pediatrics*. 1979; 64:106-10.
- Kanthor H, Pless B, Satterwhite B, et al. Areas of Responsibility in the Health Care of Multiply Handicapped Children. *Pediatrics*. 1974; 54:779-85.
- Kenen RH. Genetic Counseling: The Development of a New Interdisciplinary Occupational Field. *Soc Sci Med*. 1984; 18:541-9.
- Khoury MJ, Newill CA, Chase GA. Epidemiologic Evaluation of Screening for Risk Factors: Application to Genetic Screening. *AJPH*. 1985; 75:1204-8.
- Kopelman LC. Protesting the Proposed Federal Regulations for Critically Sick Infants. *NCMJ*. 1985; 46:265-9.
- Lagoe RJ, Milliren JW, Baader MJ. Impact of Selected Diagnosis-Related Groups on Regional Neonatal Care. *Pediatrics*. 1986; 77:627-32.
- Lancet*. Can First-Trimester Fetal Diagnosis Be Reliably Evaluated? *Lancet*. 1985; 735-6.
- Lancet*. Penicillin Prophylaxis for Babies with Sickle-Cell Disease. *The Lancet*. 1986; 1432-3.
- Lange K. Approximate Confidence Intervals for Risk Prediction in Genetic Counseling. *Am J Hum Gen*. 1986; 38:681-7.
- Leichtman LG, Say B, Coldwell JG. Patients in a Clinic for Children With Multiple Handicaps. A Retrospective Diagnostic Evaluation. *South Med J*. 1980; 73:1221-5.
- Lenke RR, Nemes JM. Wrongful Birth, Wrongful Life: The Doctor Between a Rock and a Hard Place. *Obstet & Gynec*. 1985; 66:719-22.
- Levinsky NG. The Doctor's Master. *New Eng J of Med*. Dec. 13, 1984; 311:24:1573-5.
- Lipkin M, Fisher L, Rowley PT, et al. Genetic Counseling of Asymptomatic Carriers in a Primary Care Setting. *Ann Int Med*. 1986; 105:115-23.
- Lorenz RP, Botti JJ, Schmidt CM, et al. Encouraging Patients to Undergo Prenatal Genetic Counseling Before the Day of Amniocentesis. *J Reprod Med*. 1985; 30:933-5.
- Manning WG, Leibowitz A, Goldberg GA, Rogers WH, Newhouse JP. A Controlled Trial of the Effect of a Prepaid Group Practice on use of Services. *N Engl J Med*. 1984; 1505-10.
- Markova I, Forbes CD, Inwood M. The Consumers' Views of Genetic Counseling of Hemophilia. *Am J Med Gen*. 1984; 17:741-752.
- Martin D. Withholding Treatment from Severely Handicapped Newborns: Ethical-legal Issues. *Nursing Administration Quarterly*. 1985; 9:47-56.
- May JJ. Impact of Diagnosis Related Groups on Medical Practice. *Am J Cardiol*. 1985; 56:16C-26C.
- Mueller RF, Sybert VP, Johnson J, Brown ZA, Chen WJ. Evaluation of a Protocol for Post-Mortem Examination of Stillbirths. *N Engl J Med*. 1983; 309:586-90.

- New Jersey Department of Health. State Dept. of Health Takes Medicare to Court: At Issue: The Outpatient Waiver. Healthline. June, 1985; 1.
- NIH Director. ACTIONS. Recombinant DNA Technical Bulletin. 8;1:17-28.
- Nolan-Haley JM. Amniocentesis and the Apotheosis of Human Quality Control. *J of Legal Med.* 1981; 2;3:347-363.
- Ortbals DW. Effect of Medicare/Medicaid Reimbursement Policies on Diagnostic Methodology in the Physician's Office. *Diagn Microbiol Infect Dis.* 1986; 143S-150S.
- Passarge E, Eckerland B, Stephan U. Genetic Counselling in Cystic Fibrosis. *Eur J Pediatr.* 1984; 143:54-57.
- Poikolainen K, Eskola J. The Effect of Health Services on Mortality: Decline in Death Rates From Amenable and Non-Amenable Causes in Finland, 1969-81. *Lancet.* Jan. 1986; 199-202.
- Relman AS. Who Will Pay for Medical Education in Our Teaching Hospitals? *Science.* Oct 5, 1984; 226:20-3.
- Rhee S-O, Lyons TF, Payne BC, et al. USMGs Versus FMGs—Are There Performance Differences in the Ambulatory Care Setting? *Medical Care.* 1986; 24:248-58.
- Richardson D, Rosoff A, McMenamin JP. Referral Practices and Health Care Costs—The Dilemma of High Risk Obstetrics. *J Legal Med.* 1985; 6:427-64.
- Robbins A, Freeman PK. Congress Looks at the Evidence. *J Public Health Policy.* 1985; 335-9.
- Robertson JA. Legal Issues in Fetal Therapy. *Sem in Perinatol.* 1985; 9:136-42.
- Rowley PT, Lipkin M, Fisher L. Screening and Genetic Counseling for Beta-Thalassemia Trait in a Population Unselected for Incomparision of Three Counseling Methods. *Am J Hum Genetics.* 1984; 36:677-689.
- Schwartz WB, Newhouse JP, Williams AP. Is the Teaching Hospital and Endangered Species? *N Engl J Med.* 1985; 313:157-62.
- Shear CS, Wellman NS, Nyhan WL. Phenylketonuria: Experience with Diagnosis and Management. *Heritable Disorders of Amnio Acid Metabolism.* 1974; John Wiley Sons, Inc. 141-59.
- Siu AL, Sonnenberg FA, Manning WG, et al. Inappropriate Use of Hospitals in a Randomized Trial of Health Insurance Plans. *N Eng J Med.* 1986; 315:1259-66.
- Steinwachs DM, Weiner JP, Shapiro S, et al. A Comparison of the Requirements for Primary Care Physicians in HMOs with projections Made by the GMENAC. *N Engl J Med.* 1986; 314:217-22.
- Stern RS, Epstein AM. Institutional Responses to Prospective Payment Based on Diagnosis-Related Groups—Implications for Cost, Quality, and Access. *N Engl J Med.* 1985; 312:621-27.
- Stewart N. Women's Views of Ultrasonography in Obstetrics. *Birth.* 1986; 13:39-43.
- Tammelleo AD. If You Want To Stop Treating a Patient. *RN.* 1986; 59-60.
- Taub S. The Current Status of Actions for Wrongful Life and Wrongful Birth. *Leg. Med.* 1985; 180-95.
- Van Regemorter N, Dodion J, Druart MA, et al. Congenital malformations in 10,000 consecutive births in a university hospital. *J Pediatrics.* March 1984; 386-90.
- Whalen WA. Guide to Review Activities in PPSD Hospitals. Connecticut Peer Review Organization (CPRO). 1984; 1-28.
- Wright CH, Gardin TH, Wright CL. Obstetric Care in a Health Maintenance Organization and a Private Fee-for-Service Practice: A Comparative Analysis. *Am J Obstet Gynecol.* 1984; 149:848-56.
- Young ID. Ethical Dilemmas in Clinical Genetics. *J Med Ethics.* 1984; 2:73-6.
- Young RS, Jorgenson RJ, Shapiro SD. Efficiency of and Patient Preference for Three Counseling Formats. *J Craniofacial Genet & Devel Bio.* 1986; 6:3-14.